

PSP/MATTERS

SPRING 2021

ALSO INSIDE

**The Research
Information Day and
Strategy Launch**

**Eating well whilst
living with PSP
& CBD**

**Local Groups
meeting via Zoom**

**Fundraising through
the pandemic**

A photograph of a woman with blonde hair, wearing a yellow beanie, a blue coat, and pink sneakers, pushing a man in a silver wheelchair. The man is wearing a grey flat cap, glasses, a dark jacket, blue jeans, and brown loafers. They are outdoors on a paved path with trees and a grassy area in the background.

**“WE WANTED TO
HELP IMPROVE DAD’S
QUALITY OF LIFE”**

WHERE THERE'S A WILL...

We believe that with more funding we can improve diagnosis and treatment, with the ultimate goal of finding a cure for PSP & CBD.

What if your lasting legacy could be a cure for PSP & CBD? Leaving a gift in your will could make a huge difference in beating these devastating diseases forever. Once you've remembered your loved ones, consider being part of the global fight to end PSP & CBD.



**YOUR
LASTING
LEGACY
COULD
MAKE
HISTORY**

pspassociation.org.uk/fundraising/legacy



WELCOME

The past 12 months have been a tough slog for many of us as the world closed down whilst we continue to fight COVID-19 and protect our loved ones.

Despite the challenges the ongoing restrictions have brought, both emotionally and financially, hope has been shining through in the form of community kindness, support and fundraising. The PSP &

CBD community are no exception to this, and you will read plenty more about the support you've been helping us to provide in this edition of PSPA Matters.

Of course, our Support Grants were launched thanks to your response to our Coronavirus Emergency Appeal last summer, and already we are seeing the huge difference these are making to peoples' lives.

The upkeep of your wellbeing has been at the forefront of our minds during this time. As such we've pulled together some great tips for eating well and ensuring a good nutritional balance is maintained, even if you experience problems swallowing.

We have to acknowledge how everyone's newly found Zoom skills have helped us to deliver the well-attended Research Information Day (see pages 8 to 11) as well as to continue our Local Group support and virtual awareness raising (see page 32).

Throughout the magazine, you will also read inspiring stories from our amazing supporters who have not let the pandemic restrictions get in the way of fundraising in honour of their friends and family, and to support our vital work.

It is such stories, which sit at the heart of the charity, motivating Trustees and staff members alike to continue to develop our services for the PSP & CBD community. As the vaccination programme continues, and restrictions begin to lift next month, we look forward to continuing to work with you to do this.

As always, thank you for everything you do for PSPA.

Andrew Symons, Chief Executive

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PSPA MATTERS WELCOMES NEW EDITOR!

We are pleased to welcome PSPA's Communications Manager, Helen Chapman, as the new editor for PSPA Matters.

Helen joined PSPA in December 2019 to provide in-house communications and marketing support to the charity. She took over the reins for PSPA Matters this January from Mel Barry who has done a fantastic job of developing the magazine since 2017. Thank you, Mel.

Helen is looking forward to working with readers to write useful and inspiring articles about life with PSP & CBD.

If you would like to share your experience of PSP or CBD, whether it is about caring for a loved one, tips for managing symptoms, support PSPA has provided your family or fundraising activities, please get in touch.

You can contact Helen at communications@pspassociation.org.uk or by calling 01327 356135

10,000 VOICES

10,000 VOICES CAMPAIGN

On 28 February, International Rare Disease Day, PSPA launched a new awareness raising campaign called 10,000 Voices.

The campaign was developed after recent research indicated there could be up to 10,000 people living with PSP & CBD in the UK at one time.

Since 91% of PSPA supporters shared they hadn't heard of the conditions before their diagnosis, the 10,000 Voices campaign aims to raise awareness of PSP & CBD so more people can spot the signs and symptoms, diagnosis can be made earlier and those diagnosed are referred to the appropriate services quickly ensuring the right care and support.

As part of the campaign, PSPA is calling on supporters to get involved by lobbying their Member of Parliament, sharing Red Flag posters with their local GP surgery and, pledging support on social media.

To read more about the campaign and download useful resources such as our template letter, pledge cards and Red Flag posters, please visit pspassociation.org.uk/get-involved/raise-awareness/10000-voices-campaign/





2020 CHRISTMAS BAUBLE APPEAL UPDATE

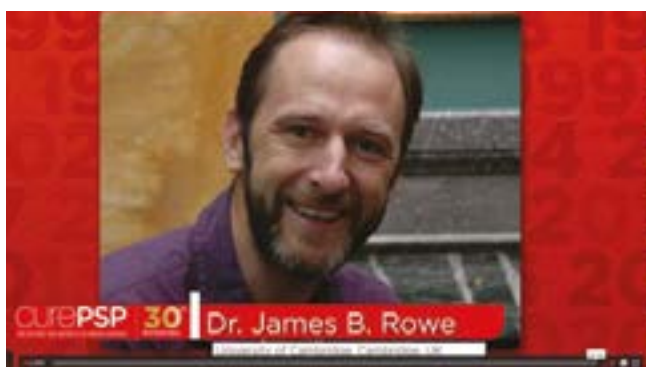
Thank you to everyone who supported our Christmas Bauble Appeal between October and December 2020.

The appeal raised approximately £10,000 along with collecting a huge number of family messages for loved ones, which we placed on the PSPA Christmas Tree.

CHRISTMAS TREE MESSAGES FOR LOVED ONES FROM PSPA SUPPORTERS.

The funds raised from the appeal will be used to help continue to fund our Helpline and Information Service, which supported more than 5,000 people last year.

THANK YOU FROM EVERYONE AT PSPA



PSPA TRUSTEE RECEIVES CUREPSP STANDOUT ACHIEVEMENT AWARD

Congratulations to PSPA Trustee, Professor James Rowe, who received CurePSP's Standout Achievement Award during the charity's 30th Anniversary celebrations on 7 December 2020.

Professor Rowe, said: "I was delighted and honoured that our work here in Cambridge was recognised in the Standout Achievement Award, from CurePSP. The fight against PSP needs a collaborative and interdisciplinary approach, that tries to bring together advanced biomedical technologies with excellence in clinical care, guided by the priorities of people affected by PSP. The 30th anniversary celebration was a powerful reminder of progress made from research, with hope for transformative treatments and prevention of PSP & CBD."

REVISED GP GUIDE AVAILABLE IN APRIL

Our GP Guide has recently been reviewed and updated, with assistance from Professor James Rowe. The guide provides information on PSP & CBD with a focus on diagnosis and early referral, improving quality of life and timely involvement from a Multidisciplinary Team.

Thank you to the Scottish Government for their financial support of the production of this updated guide.

The guide will be available in April to download from our website at pspassociation.org.uk/information-and-support/for-professionals/resources-for-professionals/

Alternatively, contact our Helpline on 0300 0110 122 or helpline@pspassociation.org.uk if you would like a copy to be posted to you.

If you would like to support our work. There are many ways you can make a donation to PSPA.

- Phone – call 01327 322414
 - Text – text **TEAMPSA** to **70085** to donate **£5**
 - Set up a regular gift online pspassociation.org.uk/fundraising/donate/
- Every penny you give will make a difference to people with PSP & CBD, their carers and family. Your donation will fund our information and support services and will be invested in research into PSP & CBD.





UPDATE ON VOICE BANKING

If you are a regular reader of PSPA Matters you will remember in the last edition we featured an article on Lisa Rodriguez, who is living with a diagnosis of CBD. Lisa shared a really positive experience of voice banking and we hope it encouraged people to look into the service with their speech and language therapist.

If you are considering banking your voice you may be pleased to know that we are now working with an amazing organisation called SpeakUnique who offer this service to help people with communication difficulties.

SpeakUnique offer three different voice banking services depending on the individual's speech needs:

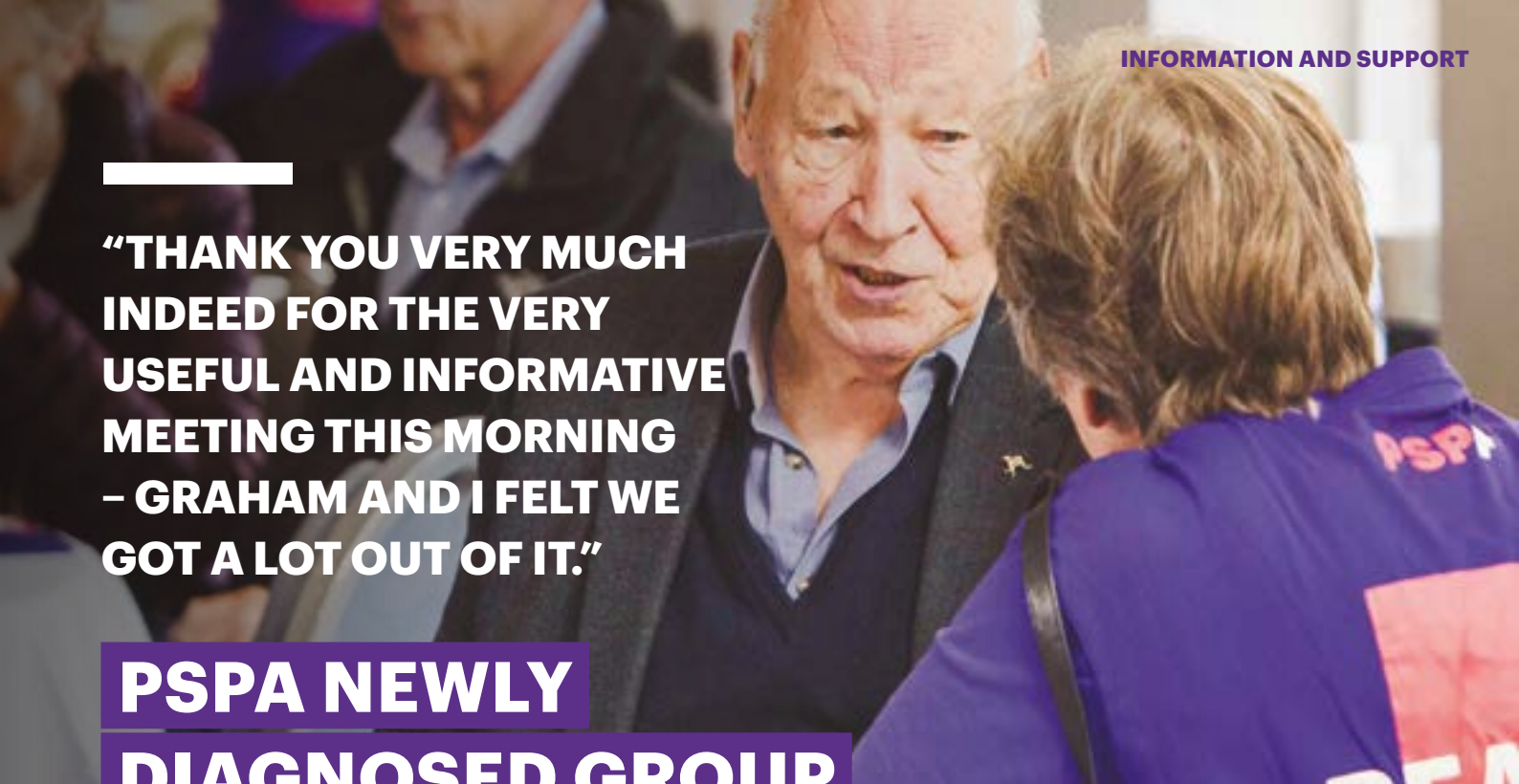
1. Voice Build is for those who have not yet experienced changes to their speech and wish to create a synthetic replica of their own voice. You will be asked to record between 150 and 300 sentences. Depending on the strength of the voice and how tired people can become this can take different lengths of time for different people. For some it may take hours but for others it may take weeks.

2. Voice Repair is for those whose speech has already started to change, e.g. through slurring or slowness. These changes can be "repaired" in the synthetic voice to create a healthy sounding voice. Fewer phrases will need to be recorded.

3. Voice Design is for those who have no intelligible speech and wish to use old recordings of their voice to create a personalised synthetic voice, or alternatively wish to use voice donors (with matching regional accent, gender and age) to create a bespoke synthetic voice.

If you would like more information on funding for voice banking please contact the PSPA Helpline on **0300 0110 122** – helpline@pspassocation.org.uk or www.speakunique.co.uk





**“THANK YOU VERY MUCH
INDEED FOR THE VERY
USEFUL AND INFORMATIVE
MEETING THIS MORNING
– GRAHAM AND I FELT WE
GOT A LOT OUT OF IT.”**

PSPA NEWLY DIAGNOSED GROUP

Have you, or someone you know been recently diagnosed with PSP or CBD? If so, why not think about joining our PSPA Newly Diagnosed Group.

The group has been set up to provide support and information to people who have been diagnosed within the last six months. It also offers an opportunity for anyone newly diagnosed to meet people who are coming to terms with their diagnosis, those wanting to know more about symptoms, how to navigate services and offer peer support.

Meetings are offered as a block of six. We hope people will then move onto their PSPA Local Group or get together as friends.

Local Groups are a great source of support but inevitably there will be a mix of people at different stages of their disease progression which can often be very difficult for those newly diagnosed.

At every Newly Diagnosed Group meeting there is a representative from the PSPA Helpline as well as a health professional from the multidisciplinary team. This provides the opportunity for those attending to talk about living with symptoms of PSP & CBD and hear about the information and support that is available through PSPA.

We are currently halfway through our first six-month block and the next series of Newly Diagnosed Group meetings will be starting in May.

Carol Amirghiasvand, Director of Engagement, said “The Newly Diagnosed Group has been a great success. Attendance has been excellent, and everyone has been very supportive. We have also had positive feedback from health professionals in general, who are signposting people to the group as they feel this type of meeting is very much needed for newly diagnosed people”.

Speakers and dates for May to October 2021 meetings

Wednesday, 26 May – Anna Kent, Neurological Conditions Clinical Specialist
Wednesday, 30 June – tbc
Wednesday, 28 July – tbc
Wednesday, 25 August – tbc
Wednesday, 29 September – Dr Timothy Rittman, Neurologist
Wednesday, 27 October – tbc

If you would like to join the next Newly Diagnosed Group starting in May, please contact the PSPA Helpline on 0300 0110 122 or email [**helpline@pspassociation.org.uk**](mailto:helpline@pspassociation.org.uk)

If you are a health professional who would like to support us with any of the meetings please contact [**carol.amirghiasvand@pspassociation.org.uk**](mailto:carol.amirghiasvand@pspassociation.org.uk)



Read more about how our Local Groups are staying in touch during the pandemic on [page 12.](#)



BRINGING RESEARCHERS TOGETHER WITH PATIENTS

On Saturday 23 January, around 100 people joined our Research Manager, Dr Wendy Edwards, and our Research Committee Chair, Professor Nigel Leigh, for an informative online Research Information Day and the official launch of the new PSPA Research Strategy.



The day brought together patients, carers, health professionals and researchers, in an informal way, to share knowledge, answer questions and learn. As patient engagement is now at the forefront of research, bringing the PSPA community together in this way, will ensure the voices of people living with PSP & CBD, as well as their carers, are heard by all stakeholders.

A range of leading researchers in the field of PSP & CBD spoke at the event.

Researchers including Dr Ed Jabbari, who provided a fascinating update on the progress of the PSPA funded PROSPECT study and talked about new biomarkers for PSP during a session Chaired by Professor Huw Morris, from UCL.

University of Cambridge researchers, Dr Negin Holland and Dr Maura Malpetti talked about how brain imaging and PET scanning has led to new knowledge about the causes of PSP & CBD, and how

“THIS WAS A WONDERFUL INITIATIVE AND VERY INFORMATIVE DAY WHICH EXTENDED OUR KNOWLEDGE.”

this knowledge will lead to new targets for clinical trials of new drugs, in a session Chaired by Professor James Rowe.

Dr Chrystalina Antoniadou told us all about the OXQUIP study which is looking at quantifying PSP & CBD symptoms as a way of assessing progression of the conditions. She also noted that they have received further funding to recruit more patients into this study.

We were delighted to hear from Dr Diane Swallow from the University of Aberdeen, who launched her findings from the PSPA and Chief Scientist Office for Scotland jointly funded fellowship on an improved understanding of the diagnostic process and how this has the potential to inform and improve many areas of care and research in PSP & CBD.

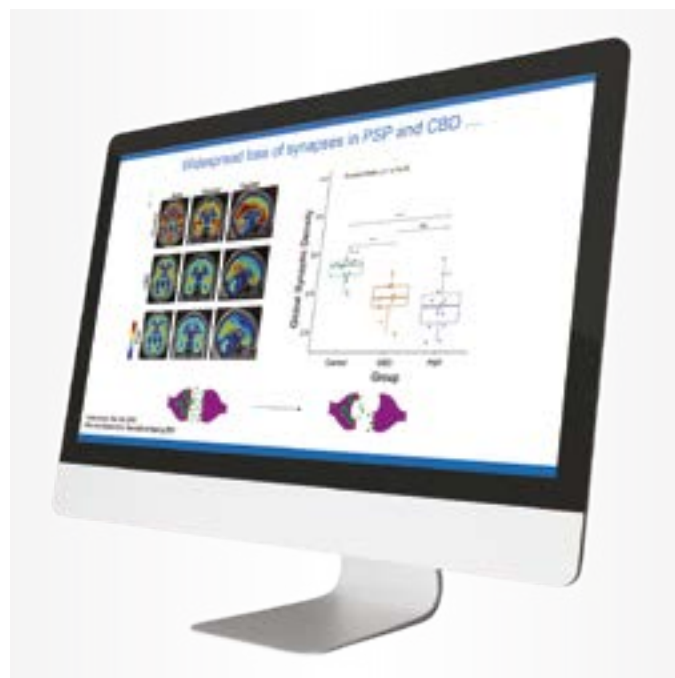
Our final speaker was Dr Edoardo de Natale who, during the afternoon session, presented on a new research study which is taking place in London and is studying the effects of a tracer on PSP progression.

Towards the end of the day, which took place via Zoom, we launched the new PSPA Research Strategy and the Patient and Carer Voices in Research Network.

Dr Wendy Edwards, said of the launch, “This is an exciting time for PSPA. The new strategy is the product of a consultation in 2020 with a wide range of stakeholders from patients to carers to neurologists and researchers and we look forward to utilising the results to help inform our research decisions going forward.”

“WE LEARNT A LOT AND ALTHOUGH SOME OF THE BIOLOGY IS COMPLICATED, IT WAS EXPLAINED CLEARLY AND INFORMATIVELY. IT WAS A GOOD WAY FOR MY HUSBAND TO BECOME MORE INFORMED WITHOUT ME ‘PREACHING’ TO HIM.”





The day ended with an opportunity for patients and carers to have a shared voice by taking part in an interactive session discussing research related questions led by the PSPA Research Manager and Director of Engagement, Carol Amirghiasvand.

Carol said “It was great to bring so many people together to discuss PSPA research and ensure the voices of those we support are heard as research into PSP & CBD continues. We had a fantastic response to our research priorities survey last year and the interactive session was a great opportunity to engage with supporters to gain more insights into peoples’ thoughts around what types of research studies they would like to participant in.”

“ALL THE TALKS WERE INTERESTING AND ENCOURAGING IN TERMS OF PROGRESS IN UNDERSTANDING AND SEEKING AVENUES TO FIND BETTER WAYS TO SLOW AND EVENTUALLY DEFEAT PSP. IT WAS GOOD TO SEE SO MANY LEADING NEUROLOGISTS THERE, INCLUDING NIGEL LEIGH, HUW MORRIS AND JAMES ROWE.”

If you missed taking part in the day, you will be pleased to hear that we recorded the event. You can view the morning and afternoon sessions of the event, as well as download the programme for the day at: pspassociation.org.uk/research-information-day-and-strategy-launch/

Read more about how you can take part in any of the research studies which are currently recruiting new patients pspassociation.org.uk/research/patient-carer-voices-in-research/



Turn to page 38 to learn more about our Patient and Carer Voices in Research Network

LOCAL GROUPS MEETING ON ZOOM

Becoming more IT proficient is just one of the positive things to come out of the past 12 months. Who would have thought we would be Zooming this and Zooming that? It has brought people together in a way we never thought possible. Meeting virtually was for the 'youngsters' but here we are dialling into meetings with our friends and family on a regular basis.

When the first lockdown happened, we decided to move the majority of our Local Group meetings online. We knew this was the only way we would be able to offer any kind of support to those who enjoyed attending their Local Group meetings and for people to keep in touch with friends they had made through PSPA.

We had a slow start. Just a few groups tried it initially but now we are running 31 groups, including our Newly Diagnosed Group and our Youth Support Group. Attendance is variable but even if there are only a few people in the meeting there is always so much to talk about. People say it's lovely to be able to see each other and catch up with what everyone has been up to.

In addition, having the opportunity to move to virtual meetings has meant we have been able to offer group meetings in areas that haven't had Local Groups before. We now offer group meetings in Northern Ireland and in the South West Peninsula region. It has also given people who were not able to get to their Local Group due to their caring role or transport issues, the opportunity to attend which has been great.



Where possible the meetings are led by the Local Group Coordinator but if this is not possible one of the PSPA Helpline Care Navigators attends.

We know you are all missing seeing each other face to face. There is nothing like an arm around the shoulder or the touch of a hand to show your support to someone but the positive thing is if you have overindulged during lockdown and can't get those trousers or that skirt on, you can just sit in some leggings. No one is going to know. You will all be back together soon but until then it's Zoom, Zoom, Zoom.

You will find dates for Local Group meetings on our website pspassociation.org.uk/information-and-support/your-pspa-support-networks/your-local-group/

Don't forget our new CBD Support Group meets on the second Wednesday of every month at 11am, starting from 10 March.

If you would like to receive invites to any of the meetings please contact the PSPA Helpline on 0300 0110 122 or email helpline@pspassociation.org.uk



PROGRESS IN SCOTLAND

It is a concerning fact that only 24% of countries worldwide have stand-alone neurological health policies. Scotland is fortunate it is included in the 24% as in December 2019 the Scottish Government published the first Scottish National Framework for Action on Neurological Conditions for 2020-2025.

The Framework is the way the Scottish Government translates their vision of people being able to access the care, support and information they need and enables them to understand their condition following diagnosis. It also signposts them to relevant resources for their changing requirements, as well as empowering people to be equally involved in decisions affecting them in the context of their wishes, wider wellbeing and circumstances.

The Scottish Framework came along with £4.5 million of funding over five-years to deliver its commitments. PSPA was delighted to have recently been successful in our application for Round one of Scottish Framework funding for 2020 - 2021.

This award will allow us to allocate dedicated project time to collaborate with colleagues in community and hospital settings to gather information on who the key health and care staff are across the 14 health board regions in Scotland. We can then use this to inform and start to build the complex picture of the routes to support for those with PSP & CBD and their families. In this way, we would be able to begin to plot the connections with professionals that people and their families can expect throughout the progression of their conditions as well as identify possible gaps in care, any duplications or highlight where things can go wrong. We will also use the project as an opportunity to introduce, at every contact, the support available at PSPA including

our resources for patients and professionals (such as the newly updated Guide to PSP & CBD for Occupational Therapists).

Gill Dickson, PSPA Scotland Country Manager said, "We are delighted to be one of only 17 projects that were accepted for funding from Scotland's first National Action Plan on Neurological Conditions. It presents a real opportunity to make a difference for people living with PSP & CBD in Scotland.

We hope when our project is completed at the end of March 2021 we have improved awareness of PSP & CBD particularly with decision makers and health and social care professionals so they can recognise the conditions, and have the skills and knowledge to help those affected access the appropriate services."

PSPA is currently considering a proposal to submit to the second round of applications for 12 to 18-month projects to start in April 2021. The Scottish Government will be looking for collaborative and innovative proposals across organisations to support the implementation of the Neurological Care and Support Framework and PSPA will ensure our planned activity in Scotland continues to align to the framework commitments, aims and vision.

"WE WANT TO RAISE MONEY TO AID AWARENESS AND FUND RESEARCH."

In March 2020, Maria Burton and friends got together to start raising awareness of PSP and funds for PSPA, after their friend Malcolm Greenwood was diagnosed with the condition in December 2019. Maria updates us on the 'TeamMalc' activities so far and what they have planned for 2021.

"It all started last March, just before the first lockdown came in, and after we had all got our heads around Malc's diagnosis. Most of us have known each other since we were teenagers so we wanted

to find out more about the condition and also raise awareness. Initially we set up something called the 'Rainbow Do', where 20 of us pay £10 per person, each month, to contribute towards a get together





MALCOLM AND HIS DOG JASPER

at Christmas. To help fundraise for PSPA, we also decided to donate £5 per person a month, from this fund, and have raised approximately, £1,500 so far. Unfortunately, due to the restrictions, we were unable to meet at Christmas, so we've made the decision to continue contributing to the 'Rainbow Do', and will review again at Easter.

In the summer, our activities grew, with the introduction of the '100 Club', which currently has 135 members. The club holds a monthly prize draw, tickets are £2 each and the winner receives 20% of what is raised each month, with the rest being donated to PSPA. Currently the '100 Club' has raised £2,300.

As a keen cyclist, Malc's sister, Denise, and two friends, then decided to set themselves a cycling challenge and signed up to take part in the Prudential Ride London event on 16 August 2020.

Unfortunately, again due to the COVID-19 restrictions, the Ride London event didn't take place. Instead, the organisers encouraged people to take on the challenge, locally. Since Denise and her friends, were cycling in the Peak District, they decided, instead of cycling 100 miles, they would cycle twice the elevation gain in half the distance and they raised £3,000 in doing so.

Since there are so many of us involved in 'TeamMalc' activities now, we have created a monthly newsletter to help keep everyone up to date with what is going on and to also flag other initiatives people can get involved in.

Via the newsletter we have encouraged people to collect used stamps, so we can send them onto PSPA who will change them into donations. Currently, we are promoting an upcoming plant sale which we hope to hold in the spring, depending on how the vaccination roll out goes.



We have also been selling face masks in aid of PSPA and look forward to seeing Malc's nephew, James Mackenzie, run the London Marathon in October. A few of us hope to join the event as volunteers to help out at PSPA cheering stations along the route.

With all the lockdowns and restrictions taking place during this past year, the 'TeamMalc' activities have helped us to stay connected as friends as well as to raise funds to aid research into treatments for PSP, and in the future for Malc, to help with purchasing any equipment he may need.

Once we're out of lockdown we have lots more in the planning, including comedy evenings, a summer or Christmas ball, a golf day, a tennis tournament and a games night. Many people have volunteered to help with the activities. Malc is a very popular, lovely man, so it comes as no surprise.

Malc has whole heartedly given permission for his name to be used for the cause. When we told him what we were doing he said he was 'flabbergasted' and thinks it's 'absolutely amazing'."

GET INVOLVED IN 2021

If you would like to get together with friends to fundraise for PSPA like Maria is, why not help support our 10,000 Voices campaign by organising activities themed around the number 10?

You could each walk 10,000 steps or more a day for 10 days, run or cycle 10km, donate £10 each or host a virtual baking competition or quiz night. For more fundraising ideas please email fundraising@pspassociation.org.uk

HOW PSPA SUPPORT GRANTS ARE IMPROVING PEOPLES' LIVES

Thanks to the fantastic response we received to our Coronavirus Emergency Appeal, we have issued 12 PSPA Support Grants, since they were launched in August 2020. The Support Grants aim to improve the lives of people living with PSP & CBD by providing a one-off payment of up to £250 to help cover the cost of a piece of equipment or service. Here three recipients share their experience of how the grants have helped to improve their lives.



“MAINTAINING GRANDMA’S QUALITY OF LIFE IS REALLY IMPORTANT TO US.”

Ela Jones shares how receiving a Support Grant will help her grandma, who was diagnosed with PSP in 2019.

“Me and my grandad were over the moon when we found out my application for a PSPA Support Grant had been successful.

I applied on behalf of my grandma who was diagnosed with PSP in May 2019, around two years after her symptoms initially started to show, and her weight loss has been progressing alongside her illness.

Grandma has always been a really proud lady, with a keen interest in shopping. Most weeks she would visit the shops once or twice a week, so she was always really well dressed. The continual weight loss, of

around three or four dresses sizes to date, caused by choking on food, forgetting to eat and refusing food due to paranoia, has been difficult to see.

I spotted a newsletter from PSPA highlighting the Support Grants, and not long after, grandma’s community psychiatric nurse mentioned it to me also. This inspired me to apply for a grant to help buy grandma new clothing, at regular intervals, to help keep up with her weight loss.

Maintaining grandma’s quality of life is really important to our family and we feel clothing is central to this so the grant will be really helpful. We gave her some new clothes as a nice treat for Christmas but we have also planned ahead, and bought some smaller sizes so she looks good as her weight loss continues.

Grandma is happily living in a specialist dementia unit, where her every need is catered for. She moved there in June 2020, after her symptoms progressed rapidly and caring for her at home became too much for my grandad, my mum and me.

We do get to visit grandma at the home. They allow one visitor at a time inside and up to three visitors outside the window. It will be great to see her in her new clothes.

I would definitely recommend applying for a PSPA Support Grant. The process is really easy and as care needs of loved ones increase, it’s great to have funding support available.”



“YOU COULD SEE ON HER FACE HOW HAPPY MUM WAS TO SEE HER GRANDCHILDREN.”

Michael Jones applied for a PSPA Support Grant to help purchase an iPad for his mum, who was diagnosed with PSP at the end of 2019.

“I heard about the grants in an email from the Norwich Local Group Coordinator and it got me thinking how it could help mum.

I phoned the PSPA Helpline to get some more information about the grants. They were extremely helpful and patient with me, running through the whole application process and the types of items and services we could potentially apply for a grant to help us with.

The Helpline highlighted a healthcare professional needed to write the application and so I spoke to mum’s speech and language therapist about whether the grant could help fund an iPad.

Since mum can struggle to get her words out at times it can lead to periods of silence on the phone, whilst she thinks about what she wants to say. I thought an iPad could really help mum with calls, providing a larger screen for Facetime so we could see her and know when she was processing her thoughts. It would also give her some face-to-face contact during the lockdown too.

Mum’s speech and language therapist agreed this would be a great aid and between us we put together a case for a grant to help cover the costs.

I found out the application had been successful just two or three weeks after we submitted it. It was brilliant news, which gave us all a bit of a boost.

2020 was a tough year, with the COVID-19 pandemic causing so many delays with the arrangements for a care package and funding to help adapt mum’s bathroom. So, this was a really welcomed piece of good news which meant my kids could see their nana again and mum felt well supported by PSPA.

We made our first Facetime call with mum during the weekend of 7 November, for my daughter’s 8th birthday celebrations. You could see on mum’s face how happy she was to see her grandchildren for the first time since March. The kids were really happy too and were dashing about the house bringing things to show mum.

Hopefully, once mum has had more practice using the iPad, she will be able to access the Zoom Local Group meetings too, which will give her another link with the outside world.”

“WHERE THERE’S A WHEEL, THERE’S A WAY.”

Kate Wilsea applied for a PSPA Support Grant with her mother Sue, after PSP began to impact her dad’s love of walking.

“My Dad, Mike, was finally diagnosed with PSP in June 2020, at the age of 72 and after experiencing symptoms since 2017.

I forwarded an email from PSPA, detailing the Support Grants, to the rest of the family and suggested we give it a try.

We wanted to focus on something that could improve dad’s quality of life. He’s always enjoyed going on walks and until his symptoms began, he’d been enjoying being part of a morning walking group in our village.

We felt a lightweight wheelchair would be something which would allow Mum to take him outside and let him walk for a short distance but sit back down when he needed a break and be pushed around.

I rang the PSPA Helpline twice, first to ask whether our idea of a lightweight wheelchair would meet the eligibility criteria, and then to ask what accompanying paperwork was needed and who should fill it in.

We were happy, and relieved when we found out our application for funding had been successful. This was something we could do which could have a positive impact on dad’s life, despite us not being able to change the fundamental circumstances of the illness. It also felt good to have a charity hear about Dad and agree with us that his quality of life was important.

Considering the PSPA Support Grants was a new scheme and PSPA is a small charity, with a small team, it was only approximately six weeks from my first call to them to the grant being awarded.

Even though we’ve only used the wheelchair a few times and we’re still getting used to it, it’s been great to go to the park and further afield.

Kate’s mum, Sue, adds. “I’m guessing buying a wheelchair for one’s nearest and dearest is not top of everyone’s wish list. In my case, you can add a complete lack of interest in anything with wheels – be that cars, bikes or wheelchairs! And surely nobody enjoys form filling when applying for financial support?

PSPA made all this painless: the process was straightforward and quick. The questions asked were basically what we wanted, why, and what impact it would have on Mike’s quality of life. There was no intrusiveness: we did not need to detail either Mike’s condition or our financial circumstances.

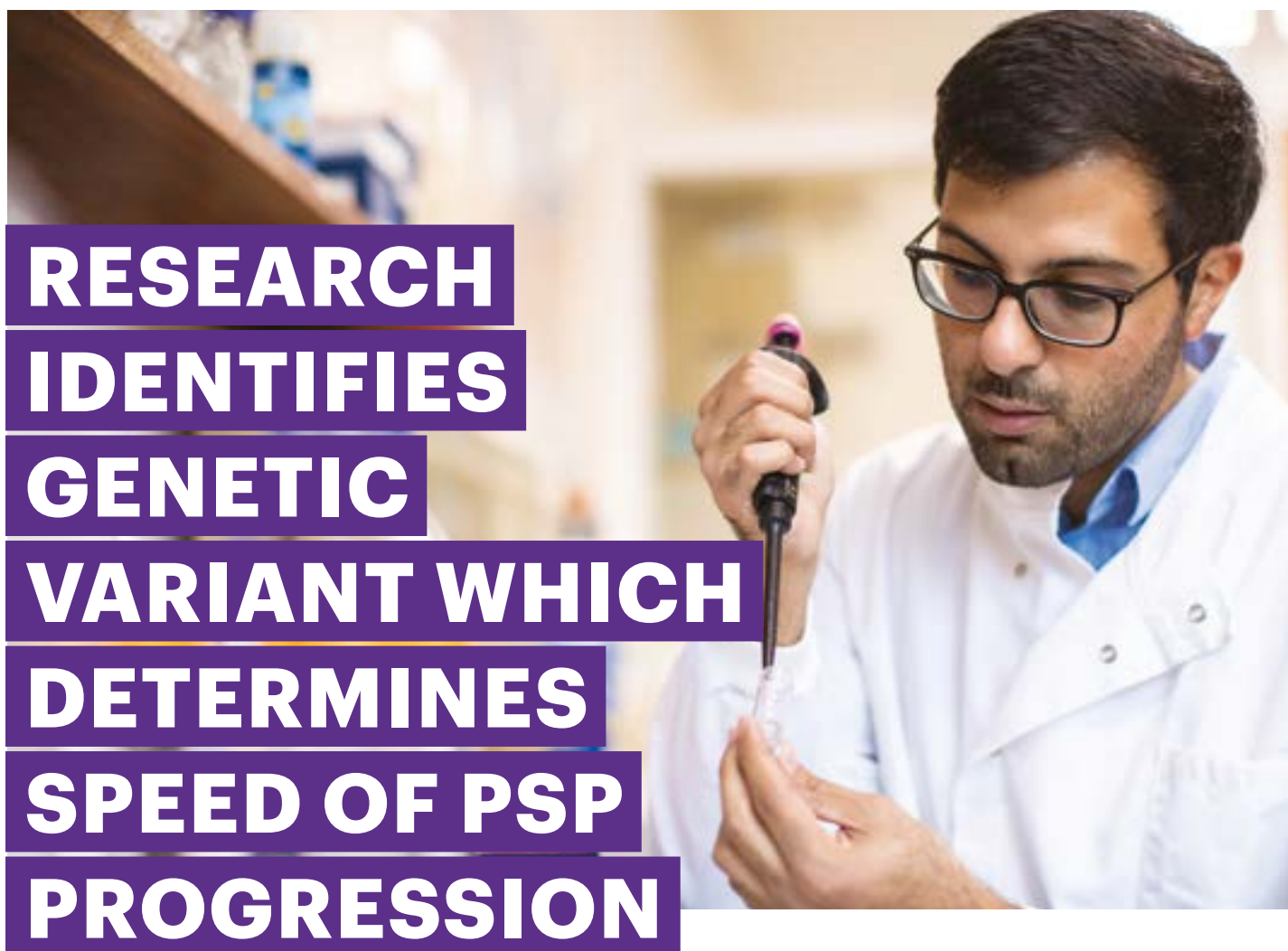
Our first visit to the local park was a joy – Mike loved it. The three of us could move forward at the same rate and he was also able to get out of the wheelchair and, holding the handles, push it in the same way as his rollator, to have a short independent walk.

The PSPA grant was much appreciated. The money itself is a great help and it provided, without any fuss, a sense of recognition we needed some support.”



For more information about PSPA Support Grants, and to download the necessary application form and guidance, please visit: pspassociation.org.uk/information-and-support/pspa-support-grants/





RESEARCH IDENTIFIES GENETIC VARIANT WHICH DETERMINES SPEED OF PSP PROGRESSION

New research has identified a genetic variant which determines how quickly PSP progresses, once symptoms begin.

The genetic variant relates to a gene called LRRK2. This gene has previously been linked to the risk of developing Parkinson's disease, so this new finding also suggests that there is a genetic link between the two conditions.

The research study is being led by Dr Ed Jabbari and Professor Huw Morris at UCL and involves just over 1,000 PSP patients, including those taking part in the PSPA-funded PROSPECT study. Dr Jabbari was funded by a PSPA clinical research fellowship and by the Medical Research Council.

The study found PSP patients who carry one version of the LRRK2 genetic variant were more likely to progress slowly, whereas, patients who carried the less common version of the genetic variant, progressed more quickly.

Dr Wendy Edwards, PSPA Research Manager, said: "Identifying the genetic variant which determines the speed at which PSP progresses is a major development in our fight against PSP & CBD. We're keen to see what the next steps of the study will bring and how it will lead to targeted treatments for the underlying causes of the conditions."

Dr Ed Jabbari, said: "While more research needs to be done, this finding opens the potential to target LRRK2 in future clinical trials as a treatment that may slow down PSP in its tracks."

Next steps for the research, will include working out exactly how LRRK2 affects the rate of progression in PSP, and potentially related tauopathies such as CBD, with a number of potential mechanisms currently under investigation.

BUSINESSES BIG AND SMALL PLEDGE THEIR SUPPORT FOR PSPA

This January, we were pleased to announce PSPA had been selected to become Talbot Underwriting's Charity of the Year for 2021 and 2022. This exciting opportunity was thanks to a nomination made by Kelly Hooper, who works for Talbot. Here Kelly, shares why she nominated PSPA and what the new partnership has in store.

"I nominated PSPA to be Talbot Underwriting's Charity of the Year because it is a charity very close to my heart as my mum died of PSP, in December 2015. December 2020 marked the 5th anniversary of mum's death and I wanted to do as much as I could to mark this anniversary and do something meaningful and help others.

"From the time of diagnosis to mum's death was just 18 months, although she had been experiencing symptoms such as falling, choking, and being unable to move her eyes normally since early 2013. In that time, my mum went from being full of life, often out from 7am to 9pm each day to frequently staring into space and not wanting to see her friends or grandchildren for no obvious reason, when we asked she would just shrug her shoulders.

"After spending Christmas day with mum in 2013, I could see her full symptoms for myself, and we went to the GP together in January 2014. Initially, mum was diagnosed with Parkinson's in March, with the re-diagnosis of PSP following in the summer after a specialist looking at her brain scan, spotted it, having just attended a PSP awareness course the week before.



"I WANTED TO DO SOMETHING MEANINGFUL TO HELP MARK THE 5TH ANNIVERSARY OF MY MUM'S DEATH"

"By September/October of the same year, it was becoming apparent mum needed additional support and so moved into a nursing home. At Easter time in 2015, mum's condition was deteriorating and the nursing home called, telling us to go there ASAP. After then, mum never got out of bed again, she never spoke again, and could only move her thumb from that point on. Mum then died in December.

"PSP is upsetting for everyone concerned so being able to nominate PSPA, give something back for the support we received, and to help others devastated by this rare illness is a great feeling.

"It was exciting to start the New Year with the partnership with PSPA and so far, we have been busy encouraging the team to get sponsored for drinking less in January as well as organising a charity cocktail making evening via BlueJeans and a virtual Bake-Off Competition in February. We're also hoping to get staff members involved in events such as the Royal Parks Half Marathon, the Asics 10k and the London Marathon."

“I COULDN’T THINK OF A BETTER CHARITY TO RAISE AWARENESS AND FUNDS FOR THROUGH FARRINGTON BOUTIQUE”

During 2021, Farrington Boutique will kindly be donating £1 for every £10 spent in their online home décor business to PSPA.

The generous fundraising has been organised by the business owner, Jessica Farrington, after her maternal Gran passed away from PSP in November last year. Her paternal grandfather, also passed away from PSP in 2013.

Jessica said: “It was just unbelievably unfair when, three years ago, Gran was diagnosed with PSP. The best way to describe this disease is like having Motor Neurone’s, Parkinson’s and often Alzheimer’s in one go. It’s unimaginably cruel.

“It seemed apt this year to raise funds for PSPA using Farrington Boutique as the boutique logo was actually chosen to symbolise the love I have for my Gran because she loved elephants. This is my way of remembering Gran and doing something she’d wholeheartedly donate to herself. It’s also my way of contributing to a world without PSP or CBD, because I know only too well the heartache of watching this disease slowly and cruelly taking away the ones you love the most.”

Read more about Jessica’s Gran’s PSP journey and why she has chosen to fundraise for PSPA, on her website at www.farringtonboutique.com/post/we-are-now-fundraising-for-pspa



If you would like to nominate PSPA as your Charity of the Year, please contact our Fundraising Team by emailing fundraising@pspassociation.org.uk



FIRST MEETING OF PSPA'S NEW RESEARCH COMMITTEE

The new Research Committee, which is a sub-committee to the PSPA Board of Trustees, met for the first time on 4 December 2020.

PSPA's Research Committee makes recommendations to the Board in relation to the research programme of the charity, working closely with the Research Manager who acts as the Secretary to the Committee.

The Committee consider applications from universities and hospitals for funding research projects from across the UK. The Committee also get involved in reviewing the progress of the research by reading annual and final reports from the researchers that PSPA fund. Each Committee member brings a wealth of expertise not only in research but also knowledge about PSP & CBD as many are health professionals who look after patients, whilst others are at the cutting edge of the science looking at how to find new ways of diagnosing and treating these conditions. The Committee is also represented by a member who has lived experience of PSP as a carer and has a background in science research and policy.

At their first meeting in December 2020 the Research Committee discussed the new research strategy and what funding might be made available to researchers over the next five years. It is hoped small project grants will be funded

in 2021 if the budget allows, and then further funding of larger grants to support the PSP & CBD communities' research priorities going forward in line with the new research strategy.

We are delighted to welcome the ten new members and thank them all for giving up their time voluntarily to support our work.

CHAIR – PROFESSOR NIGEL LEIGH



Nigel is a Professor of Neurology at Brighton and Sussex Medical School, Emeritus Professor at King's College London, Honorary Consultant Neurologist at Brighton and Sussex University Hospitals Trust and Director of the Sussex MND Care and Research Network.

After training in general medicine and neurology he completed his PhD with Professor David Marsden FRS at the Institute of Psychiatry, London and was appointed to the University Chair of Neurology at The Institute of Psychiatry in 1989. He has received The Forbes Norris Award of the International Alliance of MND/ALS Associations, the Erb-Duchenne Prize of the German Neuromuscular

Society, and The Sheila Essey Prize of the American Academy of Neurology. His research focuses on neurodegeneration, especially MND/ALS and PSP.

MEMBERS



Professor Michele Huw is a Consultant Neurologist at Oxford University Hospitals, and Associate Professor at the Nuffield Department of Clinical Neurosciences, University of Oxford.

Her clinical work focuses on Parkinson's disease and related movement disorders. Her research within the Oxford Parkinson's Disease Centre looks at longitudinal cohort studies and biomarkers for early and prodromal Parkinson's disease, with particular focus on REM sleep behaviour disorder and how sleep affects neurodegeneration. Interests include the delivery of tractable, low cost, wearable technology that has a real impact on patient's daily lives, and imaging the human brain from prodromal to established Parkinson's.



Professor James Rowe is Professor of Cognitive Neurology and studies the mechanisms and potential treatments for PSP, Parkinson's disease and frontotemporal

dementia. He trained in medical sciences and experimental psychology at Cambridge, before clinical studies in Oxford and his PhD at the Institute of Neurology, London. After further specialist training in Copenhagen, he returned to Cambridge in 2005. He is Associate Director of DPUK, leading the academic-industrial partnership for experimental medicine. He leads the Centre for Frontotemporal Dementia and the Clinical program within the Centre for Parkinson-plus, together with regional NHS clinics for these disorders. The integration of multimodal brain imaging, genetics, pharmacology and computational modelling provides a powerful platform to understand neurological disease, and to assess the efficacy of novel treatments.



Professor Johannes Attems' research interest is neurodegenerative diseases of the ageing brain with a focus on clinico-neuropathological

correlative studies. Despite the categorisation of age associated neurodegenerative diseases into specific subtypes, such as Alzheimer's disease and

Lewy body diseases, it becomes more and more apparent the ageing brain is characterised by the presence of multiple pathologies. Hence, Johannes aims to improve the neuropathological assessment of this cerebral multimorbidity to evaluate the combined influence of various morbidities on the clinical picture as this might lead to the identification of new disease subtypes and thereby to the development of novel therapeutic strategies against age associated neurodegeneration.

Johannes is Professor of Neuropathology at Newcastle University, Honorary Consultant Pathologist at Royal Victoria Infirmary, Newcastle and Director of the Newcastle Brain Tissue Resource and of the Alzheimer's Research UK Network Centre Newcastle. He is Editor in Chief of *Acta Neuropathologica* and leads the Neurodegenerative Pathology Research Group.



Dr Boyd Ghosh graduated from St. Bartholomew's and The Royal London Medical School in 2000. Junior medical posts were carried out in London, New Zealand and Bath. He was a Neurology clinical fellow in Frenchay (Bristol) before studying for a PhD in Cambridge with Professors James Rowe and John Hodges. Research during his PhD involved atypical Parkinsonian syndromes with a particular emphasis on cognition and imaging in PSP. He is currently a consultant neurologist in the Wessex Neurological Centre in Southampton and Salisbury hospitals as well as honorary teacher at the University of Southampton. In addition, Dr Ghosh is currently Treasurer for the British Neuropsychiatric Association.

Dr Ghosh leads a specialist regional service for patients with atypical Parkinsonian syndromes, which includes PSP, MSA, CBD as well as mimics. This is a multidisciplinary clinic, collaborating with therapists in the community, ophthalmologists and the palliative care services. He has previously assisted PSPA in care pathway development and advised on several of their guides for healthcare professionals. He is principal investigator for commercial and academic studies investigating PSP and other atypical Parkinsonian syndromes. He lectures and publishes on the subject and teaches for a national course – the Parkinson's Masterclass.



Dr Alistair Church has two working roles, as a GP principal in a semi-rural practice in Gwent, South Wales, and as an Associate Specialist in Neurology at the Royal Gwent Hospital. His special interest is movement disorder, particularly atypical Parkinsonism. He is principal investigator in several pharma sponsored trials in PSP and MSA. He was part of the guideline development group tasked with updating the NICE Parkinson's guidelines in 2017. He is the present editor of Neurodigest.



Professor Amritpal Mudher is a Lab PI and Professor of Neuroscience. She graduated in 1996 with a 1st Class Hons BSc King's College London, and then gained a DPhil at Merton College, University of Oxford in 1998. Professor Mudher has studied tau biology and pathology in a number of cellular and animal models since her DPhil, first in the laboratory of Professor Hugh Perry in Oxford, and then in the laboratory of Sir Simon Lovestone at the Institute of Psychiatry in London.

In 2001, Professor Mudher began her independent research career as an Alzheimer Society fellow and then as a lecturer at the University of Southampton in 2004. As her team grew, her interest in tauopathies deepened, and her experimental portfolio diversified to include Drosophila models and more recently human tissue-based models (post-mortem, resected, and iPSC cells – in collaboration with other scientists in Southampton).



Professor Diane Hanger graduated from the University of Leeds, followed by several years working in the pharmaceutical industry (Pfizer and GlaxoSmithKline), before undertaking a PhD at the University of London. Since then, Professor Hanger has worked as an academic at King's College London where she leads a group working on the roles of tau and alpha-synuclein in a range of neurodegenerative diseases. Professor Hanger has a long-standing interest in the biochemistry and consequences of protein modifications, including phosphorylation and truncation, on protein function. The particular focus of Professor Hanger's research is on disease-related abnormalities in tau protein in PSP, Alzheimer's disease and related disorders, and

how these changes in tau impact on the normal function of nerve cells.



Professor Siddharthan Chandran is the Director of Centre for Clinical Brain Sciences, Edinburgh Neuroscience, Euan MacDonald Centre and Anne Rowling Regenerative Neurology Clinic.

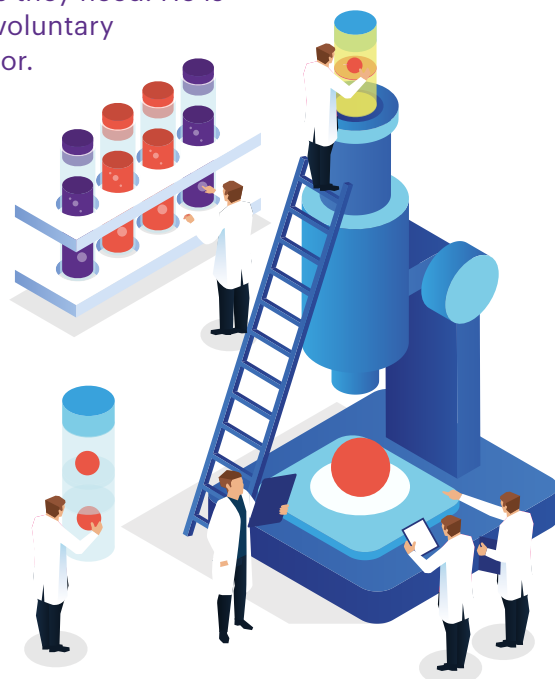
Professor Chandran graduated with a Bachelor of Medicine from Southampton University. His neurology training took place at the National Hospital for Neurology and Neurosurgery, UCL and University of Cambridge. He completed a PhD in developmental neurobiology at the University of Cambridge in 2000, where he was a Consultant Neurologist, University Lecturer and Fellow of King's College. Professor Chandran moved to the University of Edinburgh to become a MacDonald Professor of Neurology in 2009.

LAY MEMBER



Navin Sewak is a pharmacist and has a portfolio career spanning almost two decades across hospital, primary and social care, consultancy and most recently in the pharmaceutical industry. He is a trained health economist and has a particularly interest in the value that medicines bring to society and maximising population health.

Navin's mother lived with PSP and through both his professional and personal life he is keen to raise awareness of PSP & CBD to MPs and other policy makers to ensure patients and their families get access to the appropriate care and services they need. He is PSPA's first voluntary Policy Advisor.



RAISING AWARENESS OF CBD WITH A VIRTUAL CHALLENGE



Last year, Gordon Booth signed up to take part in the Great North Run as part of TeamPSPA. Despite the event being cancelled, Gordon found the GNRSolo a great way to continue his fundraising as well as to raise awareness of CBD.

“Every year, I try to do a different challenge and in 2020 I decided signed up to #TeamPSPA because my wife’s mum was diagnosed with CBD around six years ago.

I’m not a runner by any means, so I knew training for a half marathon would be tough but I wanted a challenge which would push me and also, with my wife’s family living in Sunderland, it all seemed to tie in nicely.

Training for the half marathon, started really well. The distances I could cover were increasing and my times were improving. The toughest thing for me was finding the time to run regularly two or three times a week, around work and family stuff.

The lockdown helped with this a bit, as it meant there was always someone at home with the kids, so I could head out for an hour or so training. Then my friends started up a Sunday challenge, which I joined, running either 5km or 10km each week.

When the Great North Run was cancelled, I was disappointed. Although the training was tough, I had committed myself to raising money for PSPA and I felt bad I might not be able to achieve it anymore.

I signed up to the GNRSolo as soon as it was introduced as it meant I could honour my commitment. I decided to take on the 40 runs in 72 days as part of my training and then on 13 September, the date the Great North Run should have taken place, I would run the full half marathon around Leeds.

Despite the initial disappointment about the event cancellation, the benefits of the virtual run included being able to raise awareness of CBD, by posting on social media after each of my 40 runs.

A friend joined me on 13 September, which really helped to keep me motivated throughout the route, and my wife and family met us half way around. They were due to meet us at the finish line too, but because we set off so fast, we got there before they had walked from the halfway mark to the end, so we had to loop around and complete the last part again.

I finished the GNRSolo in one hour and 48 minutes, which was slightly faster than I was aiming for. What was great too, was I not only met but over took my fundraising target whilst I was out completing the half marathon, which is what it was all about.”

JOIN #TEAMPSPA

If you fancy a half marathon challenge like Gordon, #TeamPSPA places for the Great North Run 2021 are now available!

Register for your #TeamPSPA place for just £20 when you commit to raise £450 or more.

Email Sarah at fundraising@pspassociation.org.uk for more information.

LOCAL SERVICES ENSURED BERYL HAS THE CARE SHE NEEDS



Brian Colliss has been the registered carer for his wife Beryl for a number of years. Here Brian shares how joined up services have really helped him choose the right care home for Beryl.

“The support started when our GP consulted with the Frailty Support Team in Lymington after I mentioned Beryl was falling asleep quickly, whilst sat in her chair, and would get angry easily when I was trying to explain things to her. She would also get things mixed up at times, and would often say ‘hurry up’ when she meant ‘slow down’ when I was speaking to her.

Initially, we thought it was dementia, however a consultant from the team came and visited Beryl at the house in October 2019. She examined Beryl and booked her in for an MRI scan. After the scan, the neurological consultant called me, Beryl, my daughter and her husband (former medical professionals) to the hospital for the diagnosis appointment. He spent a great deal of time explaining what PSP was, how the symptoms would progress and what support Beryl would need.

I feel very lucky all of the healthcare professionals we came into contact with had heard of PSP before, and had treated people with the condition previously. This meant they knew what support and adaptations we needed at home including a stair lift, hoists and wheelchairs.

I had hoped to continue to care for Beryl at home, with the help of a team of carers, who visited at regular intervals during the day. As well as support from the occupational therapists and physiotherapists from the Frailty Support Team.

Unfortunately, though, at the beginning of 2020, Beryl’s PSP symptoms progressed and she began to fall at night when trying to get out of bed. At first, with help from the Frailty Support Team, we tried to manage the risk by lowering the bed, adding cushioning on the floor either side and also installing an intercom system which would alarm me when Beryl got close to the edge of the bed. But Beryl still managed to cut her head open twice and over time I became exhausted. After some persuading, I agreed for Beryl to go into respite care for six weeks initially and that was then extended to ten.

The Local NHS and Council have been extremely helpful during this time, working together with little chasing or help from myself or my family, to provide the care Beryl needs.

In the end, for Beryl’s safety, it was felt being placed in a care home permanently would be better. I began researching care homes myself. I was astonished about the differences in prices between each of the care homes and I was struggling to navigate cost versus the care service provided.

A lady from the Council came to see me and helped me find the care home Beryl moved into on 4 December. Not only is this care home, nearby to our home, it also provides everything Beryl needs without a massive price tag. The Council have means tested our finances and will be providing some financial support for the care home which is really helpful.

Although a quiet lady, Beryl has been very pragmatic about the changes and since moving onto pureed food whilst living in respite care, is now eating well.”

TOP TIPS FOR CHOOSING A CARE HOME

Making the decision to move to a care home needs careful consideration. You will want your care home to be a comfortable and safe environment, a happy place to live, of course, you will want it to feel like a home.

How do I find a care or nursing home?

Similar to when you buy a house, you need to get a feel for what is out there. It is a good idea to create a list of possible homes where you might want to live, they may be local to where you live now or in some cases nearer to relatives who can support you in the future.

You can ask friends or family if they know of homes with a good reputation. There are a couple of websites which are helpful too:

Which? Have an online care services directory which can be found here: **www.which.co.uk/later-life-care/care-services-directory**

The Care Quality Commission (CQC) has a 'Find a care home' facility which can be found here: **www.cqc.org.uk/what-we-do/services-we-regulate/find-care-home**

You should try to visit at least a couple of homes if possible, to have a look around. Hopefully getting an opportunity to meet and chat to staff and residents. Taking a family member or friend is also a good idea, as often they see or think of things you might not. It may be possible to take advantage of a trial day to see what it is like. Some care homes suggest you move in on a trial basis before you decide if you would like to stay.

Making sure the care home can provide the level of care you need or may need in the future is important. Ask if the staff have a knowledge of neurological conditions, some may be unfamiliar with PSP or CBD, however, knowledge of other conditions such as Parkinson's, MND or MSA is helpful as is a willingness to learn more about PSP or CBD. PSPA provides professional information packs which can be passed to the staff to enhance their knowledge and it may be possible for a PSPA Education Volunteer to provide a short awareness session to the staff once you are a resident.

It is a good idea to make a list of things to look out for or ask, such as:

- Are the staff welcoming?
- What is the staff to resident's ratio at different times of the day?
- Is there always a manager or senior staff member on duty?
- Are the rooms en-suite ?
- Is there parking for visitors?
- Are visitors able to visit during mealtimes and can they eat meals with residents?
- Is there a choice of food, ask if you can see a sample menu?
- Should your dietary needs change, can the home support this?
- Can you eat in your room if you wish to?
- How clean and tidy is the home?
- Do residents have a named member of staff who is responsible for their care?
- If your needs change or increase, can the home continue to meet your needs?
- How does the home let your family know if you are taken ill?
- Is there a call bell system?
- Can you bring your own furniture and belongings?
- Does the home offer activities or trips out?
- Are staff sitting and chatting with residents?
- Are valuables covered by the home's insurance?
- Can you see a copy of the home's contract and terms and conditions?

This is by no means an exhaustive list of questions or considerations; don't feel you need to ask everything, you should think about what you feel is important to you.

Our Helpline is available 9am to 5pm and 7pm to 9pm Monday to Friday, on 0300 0110 122 or helpline@pspassociation.org.uk

Whilst we are unable to recommend specific care homes, we are able to help with suggestions of what to look for in a care home.

NEW REPORT BRINGING RARE DISEASES

'OUT OF THE SHADOWS'

Following nine months of consultation, the rare neurological disease report, titled 'Out of the Shadows', was launched by the Neurological Alliance on 12 November 2020.

As a member of the Neurological Alliance, PSPA has contributed to the report and supports the five key recommendations, which aim to establish multidisciplinary, joined-up care, treatment and support for people living with rare neurological conditions.

Advancing equality of access, awareness, diagnostic testing, mental health support and social care is essential to improving the lives of people living with PSP & CBD. And we stand with the Neurological Alliance as they call for NHS leaders, specialised commissioners, and the government to take action.

There could be up to 10,000 people living with PSP & CBD in the UK at one time, and as is commonly experienced by the 150,000 people living with rare neurological conditions in England, access to right care can be very difficult without a timely and specific diagnosis.

In December 2019, the initial findings of the PSPA funded research study PROSPECT, revealed up to 50% of the patients they saw, were initially diagnosed with other neurodegenerative conditions such as Parkinson's disease. In addition, the findings highlighted it can take up to two years, sometimes even longer, for a diagnosis to be confirmed. And this can be too late to provide the quality of the care and support the families affected should receive.

Bradley Payne is all too aware of these issues, as he and his family struggled get the answers they needed when his dad John, started to experience balance problems in 2016. Despite regularly falling backwards, a key symptom of PSP, due to the

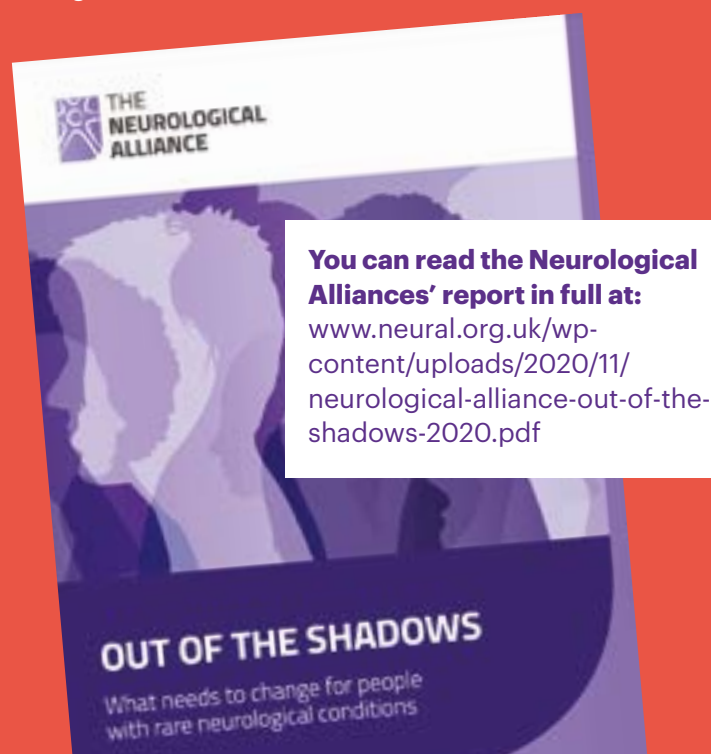
rareness of condition, health professionals struggled to find what was wrong. PSP wasn't fully diagnosed until after his dad had passed away, four years after his initial symptoms began, when it was picked up during a post-mortem examination.

Dr Wendy Edwards, PSPA Research Manager, said: "Although we fight for PSP & CBD first and foremost, in order to improve the quality of care, we must work together with others to ensure our voices are heard at both local and national levels."

"The launch of the 'Out of the Shadows' report has given us a great opportunity to come together with the Neurological Alliance, to shine a brighter light on the challenges people living with rare neurological conditions face and the crucial role charities play in providing support. We hope steps are taken to ensure diagnosis improves and access to personalised and co-ordinated care is provided."

Georgina Carr, CEO of the Neurological Alliance, said: "Taken together, rare conditions are not that rare at all – one in 17 people will be affected by a rare condition at some point in their lives, and it has been estimated that nearly a third of genetic rare conditions are neurological or have neurological symptoms. Yet, poor public awareness and a lack of investment in services for rare conditions has meant that, for too long, people with PSP & CBD and other rare neurological conditions have experienced long waits for a diagnosis, poor care coordination and insufficient information provision."

"We hope that this report will bring about a sea change in how PSP & CBD are viewed, both in the medical profession and in wider society. It's time that rare neurological conditions came out of the shadows."



You can read the Neurological Alliances' report in full at:
www.neural.org.uk/wp-content/uploads/2020/11/neurological-alliance-out-of-the-shadows-2020.pdf



PHOTOS BY:
PATRICK CONDY

“I WANTED TO TAKE ON A CHALLENGE MY DAD WOULD BE PROUD OF”

On 26 August 2020, Sam Blanchard completed a triathlon challenge, called the Trisle of Wight, to help raise awareness of PSP. Sam shares with us, details about where the idea came from, his training and successfully completing the challenge.

“My dad was just 55 years old when he received his diagnosis. It seemed such a young age to be diagnosed with a condition like PSP.

Before his symptoms began, dad was always so active. He loved cycling and was out on his bike almost every day. If he wasn't cycling, he would head out on walks or to the gym.

The progression of dad's symptoms meant he had to give up his job and driving. He switched his focus to cycling and going to the gym, but due to falling regularly, it slowly seemed like everything he enjoyed was being taken away from him.

I was feeling quite helpless and frustrated, seeing my dad's health deteriorate, which is when I had the idea to take on a challenge.

To help raise awareness of PSP, I wanted to do something big, something different, which would make people stop and think, and something my dad

would be proud of and he could engage in. My first thought was to swim around the Isle of Wight. With only five people having completed the challenge, I wasn't naïve about the efforts needed to do it. But I felt that even if I didn't succeed, it still would help draw attention to PSP.

I then added cycling to the challenge, since my dad loved it so much, and adding in running came next. This meant the challenge would be three days long, focusing on swimming, then cycling and then running around the Isle of Wight, each day.

Since I was a complete novice before I started this challenge, when I told my dad he just laughed. I told him during a long weekend to France, our last holiday together, and after his initial reaction, it sparked conversations about what sort of bike would be best and tips for swimming around the island.

With the help of Scott Dawson, the fifth person to successfully swim around the Isle of Wight, and

some work contacts, I started my structured training schedule, for what I had called the Trisle of Wight challenge, in August 2019.

Initially my training started with three months of gym work, to help prepare my body for the massive challenge. This was followed in December, by building up my swimming experience so I headed to the pool twice a day, once before work and once after.

Cycling came more naturally to me, between January and March 2020, and then once the lockdown came in mid-March, running was the easiest thing to concentrate on.

As the pandemic continued further into 2020, and more and more events were being cancelled, I realised, my initial three-day challenge might not be realistic anymore. Not wanting to fail or waste almost a year's worth of training, I shifted the plan to a one-day event including a 13km swim, a 100km cycle and a 42km run.

Despite Storm Francis hitting during my chosen week for the challenge, the weather cleared for one-day, on 26 August, which meant it was all systems go.

On the day, I was ready and, on a boat, making my way to the start of my swim at 5am. I couldn't seem to shift a bout of sea sickness, which left me feeling a bit unsteady and as I began swimming I continued to struggle with the wave pattern and sickness. This was the hardest point of the challenge, it seemed to last for ages, although I actually completed the swim in less than three hours, which was better than I had expected.

I was so happy to see my dad at the end of the swim, who had turned up unexpectedly, despite not feeling well. This gave me a great boost as I got changed and headed off on the second leg of the challenge, the 100km cycle. Despite the distance, I really enjoyed the cycle and seeing 'thank you' photos on social media, provided by the charities I was raising funds for, helped spur me on as I started my run.





Most of my run was brilliant, although towards the end, I did pull a muscle, but I managed to half limp, half run across the finish line around 10pm, that evening.

My dad was there to greet me, at the beach carpark, ringing a bell and holding a can of Guinness for me. Due to the pandemic, we couldn't have much of a celebration, but it was great to see my dad so happy. He apparently spent the day telling anyone who would listen about my challenge, even during his trip to A&E following the start of my cycle. During the car journey home, he was laughing all the way. Above everything, this is what mattered most to me that day.

It took about a week for it to fully sink in, I had successfully completed the challenge and had raised almost £11,000 for three charities in the process, including approximately £5,500 for PSPA.

Now we're into winter, and I've got my free time back, I do genuinely miss going for a swim or a bike ride. I'm looking forward to the weather getting better, so I can enjoy the activities again, whether just as a hobby, or for a new challenge!"

Read more about Sam's challenge and support his fundraising at www.justgiving.com/fundraising/trisleofwight or www.facebook.com/trisleofwight

10,000 VOICES

PLAY IN OUR 10,000 VOICES RAFFLE FOR A CHANCE TO WIN £500!

Help us continue to raise awareness of PSP & CBD, with healthcare professionals and the general public, by playing our 10,000 Voices Raffle.

Buying a raffle ticket will not only give you a chance of winning £500, but you will also be helping PSPA to raise the profile of PSP & CBD too, so:

- more people can spot the signs and symptoms
- healthcare professionals can diagnose the conditions earlier
- those diagnosed are referred to the appropriate services faster.

As an added incentive to buy and sell as many tickets as possible, whilst remaining COVID-19 safe, a luxury hamper is up for grabs. The person who buys or sells the most tickets by 12 April will win the hamper, which has been kindly donated by a PSPA Supporter!

The 10,000 Voices Raffle prizes include:

1st prize £500

2nd prize £250

3rd prize £50.

Order more tickets by contacting

fundraising@pspassociation.org.uk or call us on 01327 321410

Keep an eye on our website in April for news about PSP & CBD Awareness week, which takes place 24 to 30 May.



PSPA EDUCATION VOLUNTEERS REACHING OUT IN OUR COMMUNITIES

As well as providing information and support to people living with PSP & CBD our focus, as a charity, is to raise awareness of both conditions by offering free education and awareness events to anyone with an interest in PSP & CBD.

Recent research has shown that there could be around 10,000 people in the UK living with PSP & CBD at one time. To ensure more and more people understand the impact of living with these conditions we set up our Education Volunteer service.

Since the launch of the service our amazing volunteers have educated and raised awareness amongst almost 1,000 health and social care professionals (HSCP's). However, we still have a lot to do and our volunteers will certainly not let the pandemic stop them.

Pre-pandemic, the volunteers would visit care/nursing homes, HSCP team meetings, hospices, multidisciplinary teams as well as local organisations, like the Rotarians, Masons, and W.I's to talk about the impact of living with PSP & CBD, the work of PSPA

and share their own personal experience. Like many things the pandemic sadly put a stop to this but we really need to continue on with the great work they have already done.

So, it was time to adapt the service and thanks to the virtual platforms that we are all accessing at the moment, our Education Volunteers are now able to offer virtual education events to HSCP's using Zoom. The education sessions can be anything from 30 minutes to an hour. We already have sessions booked in for a group of GPs in Somerset as well as several nursing homes.

HELP RAISE AWARENESS

If you are a health professional and you think your team would be interested in receiving one of the sessions please contact volunteering@pspassociation.org.uk

If you belong to one of the local organisations mentioned above and would like one of the volunteers to come and talk about the great work PSPA do then please contact us.

Interested in becoming an Education Volunteer?

Why not contact our volunteering team on 01327 326137 or email volunteering@pspassociation.org.uk

“COMPLEMENTARY THERAPIES HAVE HELPED ME MANAGE MY PSP SYMPTOMS.”

Tim Willcocks shares how he believes complementary therapies have helped him manage his PSP symptoms alongside specific exercise targeted to improve balance, strength and flexibility.

“I was first diagnosed with PSP in October 2018, after discussing my increasingly wobbly gait and poor balance with my GP.

My GP referred me for an MRI scan and this revealed the hummingbird pattern often associated with PSP, and then the consultant gave me the shocking diagnosis.

As a practicing complementary therapist, myself, I feel I probably had a head start in terms of being well-informed about available therapies and how they could help. Within days I was planning a round of therapy appointments and targeted exercise regimes, especially Pilates.

Also, a therapist in Vancouver called Mihael, advised me to change to a Mediterranean diet when I was visiting my eldest son that Christmas. This involves eating plenty of alkaline foods: such as vegetables – especially green leaves – best boiled or steamed. It also means avoiding processed foods and meat, and to cut right down on cheese (my favourite!).

I like to follow the ‘Eat Right for your Blood Type’ programme, which complements the Mediterranean diet in some ways but also conflicts at times, such as with eating mackerel (good for blood type B but acidic). Eventually, I got so bogged down with all the options available, I turned to a local well trained ‘Kinesiologist’ in Malvern!

With a gentle non-invasive method of muscle testing to ascertain a ‘Yes’ or ‘No’ to each of a barrage of questions, she elicited responses from my body. Thus, the suggested course of action was tuned



specifically to my own body needs, not to any ‘general rules’.

Starting with my general diet, she gave me a massive list of ‘Yes’ or ‘No’ for different foods. Moving onto supplementation I was ‘prescribed’ a bucketful of natural supplements, costly at first while my system was being re-booted, then reducing to only two to four capsules per meal.

Currently I am checking in with her about every six to eight weeks and overall, I feel I am benefitting well from the advice.

I still have a wobbly gait and poor balance, but for a ‘degenerative condition’ I do not see that it has degenerated significantly over two years.

I believe that a good dietary regime first of all, with specific nutritional support, has created an underlying soil to keep my condition ‘stable’. Then Cranial Osteopathy/Cranio-sacral therapy treatments have assisted my balance, spatial awareness and fine motor control. And targeted exercise in the form of Pilates, plus walking and swimming, give me a balance in lifestyle.”

Benefits of complementary therapies may vary from person to person. To ensure you approach any additional treatments safely, please consult with your Neurologist or GP.



There is no denying that diet and good nutrition are essential for everyone's overall health and wellbeing. How, what and when we eat are hugely important. So, what does good nutrition look like?

At a PSPA Family and Friends day, Sharon Sexton, nutritionist and dietitian explained to the audience the importance of a balanced diet using The Eatwell Plate to help us to understand how to get the balance right.

Eating a balanced diet can improve your health and may ease problems you can experience when living with PSP or CBD including constipation, reduced bone density, weight changes and swallowing difficulties.

Basing meals on foods which are high in fibre, calcium, iron and B vitamins provide healthy calories, these are often called starchy foods, they are also filling, making us less likely to turn to the biscuit tin for a snack. Examples of starchy foods are bread, potatoes, pasta, rice, noodles and oats. Wholegrain versions of these foods can also help to ease constipation which is a common problem for people with PSP & CBD.

Protein helps to maintain muscles and strength. Good sources of protein include, meat, fish especially oily fish, eggs and nuts, as well as bean

and pulses. The latter two are also good sources of iron. You should aim to have two or three portions of protein each day.

Try to eat or drink three servings of milk or dairy foods every day to ensure you get the calcium you need. A serving is about a third of a pint of milk, a yogurt or a matchbox-sized portion of cheese. Calcium is also present in non-dairy sources such as green leafy vegetables (spinach, kale) pulses (baked beans and chickpeas), and some nuts and seeds.

Falls are unfortunately one of the symptoms of PSP & CBD and to help to keep bones healthy, less fragile and hopefully reduce the risk of fractures if you fall, it is important that you maintain a good level of vitamin D. Vitamin D is needed to help your body absorb calcium.

Most of the vitamin D we need comes from sunlight on your skin. However, during the winter and especially now that some of us are shielding due to

THE EATWELL PLATE

Use the eatwell plate to help you to get the balance right. It shows how much of what you eat should come from each food group



Texture modified meals can be an option you can explore if you are short on time or are worried about preparing foods to the correct consistency. These types of pre-prepared meals have been carefully altered to a consistency healthcare professionals have advised as easy to chew and swallow safely.

The consistency will depend on what texture your speech and language therapist has suggested. For example, a puréed diet, a minced diet, or a soft and bite-sized diet. If you have been recommended to have a purée consistency by your speech and language therapist, your food should meet several criteria, such as to all be of a consistent puréed texture, without any lumps, and not require any chewing.

Covid-19, eating foods rich in vitamin D is important. Good sources of Vitamin D are oily fish such as salmon, tuna, sardines and mackerel, eggs, meat and breakfast cereals.

There may be a time when living with a diagnosis of PSP or CBD can present complications with eating and drinking, such as swallowing difficulties. We know that coughing and choking on drinks can be a common symptom of PSP & CBD and can discourage people from getting adequate hydration. Similarly, people may find it more time consuming to eat and therefore have a reduction in their appetite. This can lead to problems with constipation, skin integrity, lethargy and disinterest in what is happening around and also weight loss.

A dietitian or nutritionist can advise on foods which can be enriched, enabling a higher calorific value to be gained from smaller meals. Most people are quite happy to make and blend their own food to a safe texture, adding small quantities of water at a time as not to lose the nutritional quality, and also ensuring their loved one still gets to experience the flavours they like most.

Of course, home blending can be a time consuming and stressful process, particularly if you are concerned about maintaining the nutritious value needed for a healthy life.

Ready-prepared texture modified meals can tick multiple boxes. Not only is the nutritional content carefully controlled and available to view on the packaging, great care is also taken to ensure the meals look appetising and are flavoursome. Just because someone has a swallowing difficulty, it doesn't mean they should have to compromise when it comes to flavour.

For more information about texture modified meals, and how you can eat and live well with swallowing difficulties, please speak to your speech and language therapist or visit Wiltshire Farm Foods website: www.specialistnutrition.com

Having won a Craft Guild of Chefs Award and Queen's Award for Innovation, Wiltshire Farm Foods prides itself on creating and delivering texture modified meals that are ideal for anyone living with swallowing difficulties. Its in-house dietitian and passionate chefs work hard to create meals that have the finest ingredients, delivering flavours you love at a texture you need, so you can celebrate mealtimes again.

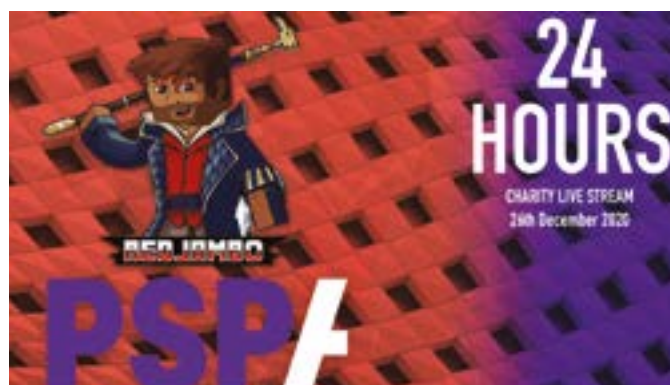
Some of the information for this article has been provided by Wiltshire Farm Foods as part of an advertising package to help contribute towards the costs of producing PSPA Matters.

FUNDRAISING THROUGH THE PANDEMIC.

Thank you to all our amazing fundraisers who have been busy challenging themselves and holding virtual or social distanced events to raise funds for PSPA and awareness of PSP & CBD, despite the COVID-19 restrictions.



THE GREAT PSPA CAKE OFF RAISED £335 AND JENNIFER DEACON WAS VOTED PSPA STAR BAKER FOR THE BEAUTIFUL FLORAL CHOCOLATE CAKE SHE BAKED FOR HER FATHER WHO HAS PSP.



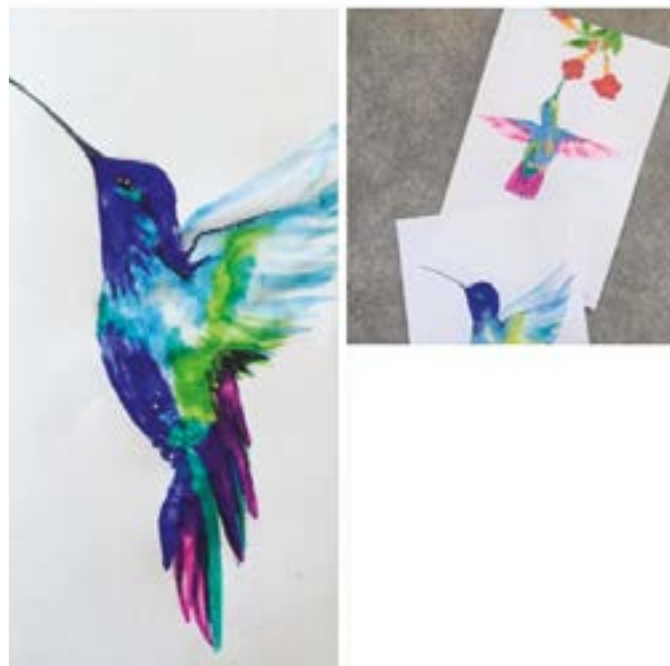
ASHTON REDMAN RAISED £1265 BY HOSTING A 24-HOUR LIVE STREAM ON HIS TWITCH TV CHANNEL. AS WELL AS FUNDRAISING ACTIVITIES, ASHTON ALSO USED THE TIME TO RAISE AWARENESS OF PSP & CBD WITH HIS FOLLOWERS.



OUR BOUNCE THE BAUBLE FACEBOOK FUNDRAISER RAISED £306 ON 1 DECEMBER AS PART OF OUR #GIVINGTUESDAY ACTIVITIES.



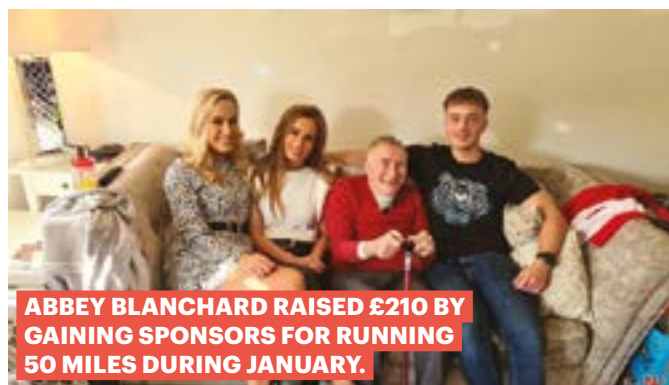
VIKKI MASON AND HER FAMILY AND FRIENDS RAISED £164.74 BY HOLDING TWO SOCIALLY DISTANCED CONCERTS FOR 60 LOCAL PEOPLE.



GEORGIA ROBINSON HAS BEEN GETTING ARTY AND CREATING BEAUTIFUL HUMMINGBIRD PICTURES FOR FAMILY AND FRIENDS IN RETURN FOR DONATIONS FOR PSPA. SO FAR GEORGIA HAS RAISED £300.



THE WOKING LOCAL GROUP HELD A VIRTUAL PSPA TEA PARTY. ALL THE CAKES WERE MADE TO SUCH A GREAT STANDARD, ALL WERE CONSIDERED WINNERS FOR 2020.



ABBEY BLANCHARD RAISED £210 BY GAINING SPONSORS FOR RUNNING 50 MILES DURING JANUARY.



PSPA FOUNDER, MICHAEL KOE, HELD TWO FUNDRAISING GOLF DAYS IN THE AUTUMN OF 2020, RAISING ALMOST £7000.



CAROL PENMAN'S DAUGHTER, ELLA SIMPSON, RAISED £180 BY SELLING HER HAND MADE CROCHET CHRISTMAS TREE DECORATIONS TO FRIENDS AND FAMILY IN HONOUR OF HER GRANDFATHER WHO HAS PSP.



HAWTHORNS RETIREMENT VILLAGE IN NORTHAMPTON RAFFLED OFF A DELICIOUS GINGERBREAD HOUSE MADE BY LINDA MCGILLIVRAY, RAISING £110.



MICHAEL CROCKER RAISED £1330 BY RUNNING 100 MILES IN 41 DAYS, FINISHING ON CHRISTMAS DAY.



“WE ARE PASSIONATE ABOUT INVOLVING PATIENTS AND CARERS IN ALL STAGES OF THE RESEARCH PROCESS.”

Following a wide consultation, PSPA was pleased to launch the Patient and Carer Voices in Research Network on 23 January, as part of the well-attended Research Information Day and Research Strategy Launch. PSPA Research Manager, Dr Wendy Edwards shares more about the new initiative and how you can get involved.

“At PSPA, we are passionate about involving patients and carers in all stages of the research process, from the review of patient information relating to a clinical trial, to ensuring patient focussed outcomes are included in a study. After all patients know their condition better than anyone can.

The Patient and Carer Voices in Research Network has been developed as a key strand to our new Research Strategy, thanks to the fantastic response from our 2020 consultation with PSPA supporters, healthcare professionals, researchers and the wider research community.

The Patient and Carer Voices in Research Network enables people living with PSP & CBD as well as their carers, to register an interest in taking part in research studies. It then helps to bring them together with research professionals who are keen to engage patients in their work.

As well as providing an opportunity for people living with PSP & CBD and their carers, to learn more about their conditions, taking part in research can also be very rewarding. Particularly if the research leads to new diagnostic tests, treatments and improvements in daily living care and support.

During the Research Information Day and Research Strategy Launch, we were pleased to hear from attendees, during a Patient and Carer Voices in Research engagement session. As part of the session, attendees were able to highlight their priorities in research, as well as the types of research they would potentially be interested in taking part in, via a live poll, which was also added to our social media profiles.

During the day, and across social media, the poll helped to identify finding treatments for PSP & CBD and aiding early diagnosis, as the key areas of interest for people who would like to take part in research as well as what people feel researchers should prioritise with their work.

As the Network develops, we hope to host more patient focussed events and workshops like this in the future.”

If you have an interest in taking part in research, you can join our Patient and Carer Voices in Research Network, at pspassociation.org.uk/research/patient-carer-voices-in-research/register-your-interest-with-us/ or by calling 01327 322410

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- ✓ **No contract. No commitment.**

For your **FREE** brochure call **0800 680 0655**
or visit us at: www.wiltshirefarmfoods.com

HERE FOR YOU

Our Helpline Care Navigators are here to support people living with and affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they can 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 a Local Group.
- 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-5pm and 7pm-9pm.

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

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