



CANDIDATE PACK FOR THE CHIEF EXECUTIVE

PSP



INTRODUCTION

Dear Candidate,

Thank you for your interest in becoming our new Chief Executive.

This is an exciting time for PSPA which celebrated its 30th birthday in 2024. We entered 2025 with a strong management team and renewed processes and systems, and with a balance sheet that will enable us to invest more ambitiously in the things that make a difference to our beneficiaries. I am excited to be recruiting a new CEO to take over strategic and operational leadership for our dedicated team and help us scale the impact we deliver across research, influencing and support.

PSPA is the only national charity offering support and information to people living with the rare, incurable, degenerative brain diseases called Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD). We provide much needed support to people and their families living with these devastating neurological conditions. We also invest in research to deepen our understanding of the conditions with the goal of reducing the time to accurate diagnosis and discovering treatments and an eventual cure. And since 2024 we have increased our investment in awareness raising of these relatively unknown diseases.

For our new Chief Executive there is enormous opportunity to grow our profile and impact. This is a time for us to drive the charity forward with confidence and ambition. You will be a visionary and strategic leader with a deep sense of social purpose and a track record of leadership in a purpose-led organisation. We are a small team, and we are looking to you to motivate and empower our people and maintain our inclusive and collaborative culture. Our life changing work relies upon the generosity of our supporters, donors and volunteers and you will understand income generation and bring exceptional communication and collaboration skills.

You will bring enthusiasm, passion and drive combined with empathy and sensitivity to our cause. Your collaborative approach and entrepreneurial spirit will enable you to lead our dedicated and committed team with purpose and energy.

I am really looking forward to working with you to move our charity forward and have even more impact for the people who need us. If you are excited by the opportunity to join us and change people's lives now and in the future, I'd love to hear from you.

Best wishes,

Rowena Ironside
Chair

ABOUT US

PSPA is the only national charity offering support and information to people living with the rare, incurable, degenerative brain diseases called Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD). The charity also supports research into diagnosis, treatments and ultimately, a cure. Until then, we exist so that no one has to face living with these conditions alone.

Since the Charity was formed 31 years ago, we have made significant progress in raising awareness and supporting people living with these devastating neurological conditions. Research estimates there are 10,000 people living with PSP and CBD in the UK. To transform the lives of everyone affected by PSP or CBD, we must drive research forward—delivering faster, more accurate diagnoses, consistent care, and immediate treatment. Breakthroughs in related neurological conditions like Alzheimer's disease are paving the way, bringing us closer to effective treatments and, ultimately, a cure for PSP and CBD.

Income averaged £1.6m over the past three years, with 2024 reaching £1.96m. PSPA currently supports around 2,100 people living with PSP, 415 people with CBD and a further 3,000 people who are supporting someone with these conditions. Alongside this we provide education and advice to over 2,000 Health and Social Care Professionals.

PSPA works in collaboration with other charities and institutions both in the UK and internationally to maximise the impact of our investments in research and awareness raising. We co-sponsor a bi-annual scientific conference with the US charity CurePSP and are also involved in the broader community of research into tauopathies.

WHAT IS PSP?

Progressive Supranuclear Palsy (PSP) is a neurological condition caused by the premature loss of nerve cells in key parts of the brain. A normal protein in the brain called tau changes shape as part of the disease process and forms into clumps (called fibrils and neurofibrillary tangles), which damage and eventually kill the nerve cells. Over time, this leads to difficulties with balance, movement, vision, speech, cognition, and swallowing.

There are no simple tests or brain scans for diagnosing PSP. In its early stages, symptoms can resemble those of other neurological conditions such as Parkinson's, Depression, Stroke or Multiple System Atrophy and misdiagnosis is common. The condition gets its name because:

- Progressive – it worsens relentlessly over time.
- Supranuclear Palsy – it damages the brain centres that enable people to control their eye movements, and these become limited as a result.

Like many other chronic conditions, there is no cure for PSP. However, many of the symptoms can be managed to help people achieve the best possible quality of life. PSP tends not to run in families, and the disease is not believed to be inherited. However, our research has shown that some people have a genetic disposition making them more susceptible.

WHAT IS CBD?

Corticobasal Degeneration (CBD) is a degenerative brain disease that affects people from the age of 40 onwards. Although there are similarities to PSP, with similar nerve cell damage and the build-up of the protein tau in certain parts of the brain, the symptoms people usually suffer are quite distinct. However, people diagnosed with CBD may go on to develop features of PSP and vice versa. The overlap between the two conditions is now well recognised. Cognitive problems are common in CBD and are often one of the first symptoms that families notice, particularly apathy, impulsive behaviour, loss of empathy and language difficulties.

OUR HERITAGE AND OUR FUTURE

PSPA provides support and information to people living with PSP and CBD, while funding research into diagnosis, care, treatments and ultimately a cure for these conditions.

The charity was set up 31 years ago by Michael Koe and his wife Sara after she received her diagnosis of PSP. Both Sara and her husband Michael were surprised and shocked at how little awareness and support existed for those affected. Our purpose is to create a better future for everyone affected by PSP and CBD. Through providing high quality support and information, supporting research, raising awareness, and putting people living with PSP and CBD at the heart of what we do.

Over the last ten years significant progress has been made with raised awareness, new services and exciting research discoveries, and there is optimism and positivity about the future of research across the whole field of neurodegeneration. As we embark upon the next ten years with a new Chief Executive at the helm, PSPA is looking to capitalise on the solid foundations built by our outgoing CEO and use our financial strength to continue pushing the boundaries to improve the lives of those affected by these diseases.





SUPPORT & INFORMATION

Enabling people to live the best life possible



RESEARCH & AWARENESS RAISING

Improving quality of life



INVOLVEMENT

Putting people living with PSP & CBD at the heart of what we do



JOB DESCRIPTION

ROLE PURPOSE

The Chief Executive will be:

- A talented leader, able to motivate and empower staff and volunteers and develop strong internal and external stakeholder relationships including with our wider community of donors and supporters.
- An inspiring and authentic individual who is confident and engaging, with a collaborative leadership style.
- A senior professional who will ensure our strategic objectives are embedded and aligned across all of our activities including policy, influencing and fundraising.

KEY RESPONSIBILITIES

Strategic Direction and Leadership

- Working with the Board of Trustees to determine a clear strategy and lead the delivery of PSPA's strategic plan.
- Providing inspiring, collaborative, positive and dynamic leadership to our staff, volunteers, campaigners, and community.
- Championing, advocating for, creating and maintaining an open, sharing culture that encourages and values diversity.
- Taking forward PSPA's commitment to digital transformation.
- Ensuring a resolute focus on impact and performance across our services and activities.

Fundraising and communications

- Working closely with our Fundraising Manager, scale our fundraising activity ensuring our strategic priorities are reflected in our ongoing development of new opportunities to ensure diverse income streams.
- Promote a collaborative internal culture focused on fundraising as the means for PSPA to become a greater force for change and be better able to deliver the vision.
- Ensure a strong and sustainable pipeline across multiple income streams and build excellent relationships with key funders.

External representation

- Identify and generate productive strategic relationships with external stakeholders, particularly with pharma and the scientific community; work collaboratively with other patient organisations in the UK to ensure the best outcomes for patients.
- Be a key spokesperson and ambassador for the charity on the key issues faced by the patient community, including diagnosis, access to specialised services, treatments and research.
- Maintain an awareness of the PSP, CBD and wider neurological disease operating environment, and a good understanding of the unmet needs of patients.
- Work collaboratively with CurePSP to understand and leverage US momentum and innovation in care delivery and research.

Governance and financial management

- Work closely with our Board to ensure that all legal and regulatory responsibilities are carried out and to support strong governance of the organisation.
- Work with the Director of Finance to ensure strong financial management, budgeting, reporting and risk management.
- Ensure systematic, timely production of accurate management accounts and maintain appropriate financial controls.



PERSON SPECIFICATION

KNOWLEDGE AND EXPERIENCE

Essential

- A history of successful and inspiring leadership within a charity or purpose-led organisation, with sound experience of business and strategic planning.
- Evidence of working with income generation teams to implement successful growth strategies, ideally with direct experience of fundraising in the non-profit sector.
- Proven track record of successfully leading change and innovation – with a particular focus on maximising the opportunities of digital and technology.
- Experience of working with a Board and of developing and maintaining robust governance, including risk strategy and management, and financial management.
- Experience of successfully raising the external profile of an organisation by seeking out and developing strong collaborative partnerships with likeminded organisations and/or through the use of effective advocacy, lobbying and external affairs campaigns.

Desirable

- Experience of working within a medical research charity.

SKILLS AND ABILITIES

- An empathy and sensitivity for our cause, with the ability to promote PSPA and build partnerships and networks with other organisations.
- Strong networking and profile-raising skills, including being adept at building influence and long-term relationships with a diverse range of stakeholders.
- Confidence in communicating in public forums and a wide variety of media and skilled in being a visible advocate for the charity.
- A creative thinker with the ability to design new approaches to income generation and service delivery.
- An exceptional manager, with the ability to cascade objectives, plan and prioritise work effectively.

STYLE AND BEHAVIOUR

- A collaborative, empowering leadership style.
- Ambitious and forward thinking with the energy to drive forward the charity's work and impact.
- A high level of emotional intelligence.
- A strong role model who leads by example and embodies the appropriate behaviours of a senior leader.
- Inquisitive and challenging; constantly seeks improvement, both in themselves and in their team. Willing to test and learn from new approaches.
- A clear commitment to inclusion, diversity, and equality.

TERMS OF APPOINTMENT

SALARY

Circa £80k

LOCATION

The PSPA office is in Milton Keynes; we would want the CEO to be able to spend two days a week in the office.

PENSION

Workplace Pension Scheme

ANNUAL LEAVE

28 days

WORKING HOURS

35 hours a week



HOW TO APPLY

We hope you will consider making an application. If you have questions about the appointment and would find it helpful to have an informal conversation, please contact chris.milo@starfishsearch.com and we will be happy to arrange a call.

To make an application, please go to <https://starfishsearch.com/jobs/chi-exe-pspa/> and click on the apply now button, with the following prepared:

- Your CV (no more than three sides).
- A supporting statement (no more than two sides) that sets out why you think this role is the right move for you and how you meet the knowledge and experience criteria.

Closing date: Monday 14th July 2025

Preliminary interviews with Starfish: w/c Monday 28th July and
w/c Monday 4th August 2025

Interviews with PSPA: w/c Monday 18th August 2025

