

A photograph of a smiling man with a beard being hugged from behind by another person. The man has a grey beard and is wearing a grey sweater. The person hugging him is wearing a pink and white striped shirt. The background is blurred.

**PSPA**

**Chief Executive**



# Welcome from the Chair

Dear Candidate,

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

This is an exciting time of change and transformation for PSPA. I joined the charity earlier this year and am delighted to be recruiting a CEO to provide strategic and operational leadership for our dedicated team, as well as to be the leading voice of the charity.

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. And, because people are often initially misdiagnosed, by the time they reach us they can feel abandoned and our support and advocacy is a lifeline. We are also pioneering research to deepen our understanding of the conditions, working with other charities and institutions in the UK and internationally to maximise the opportunities for successful outcomes.

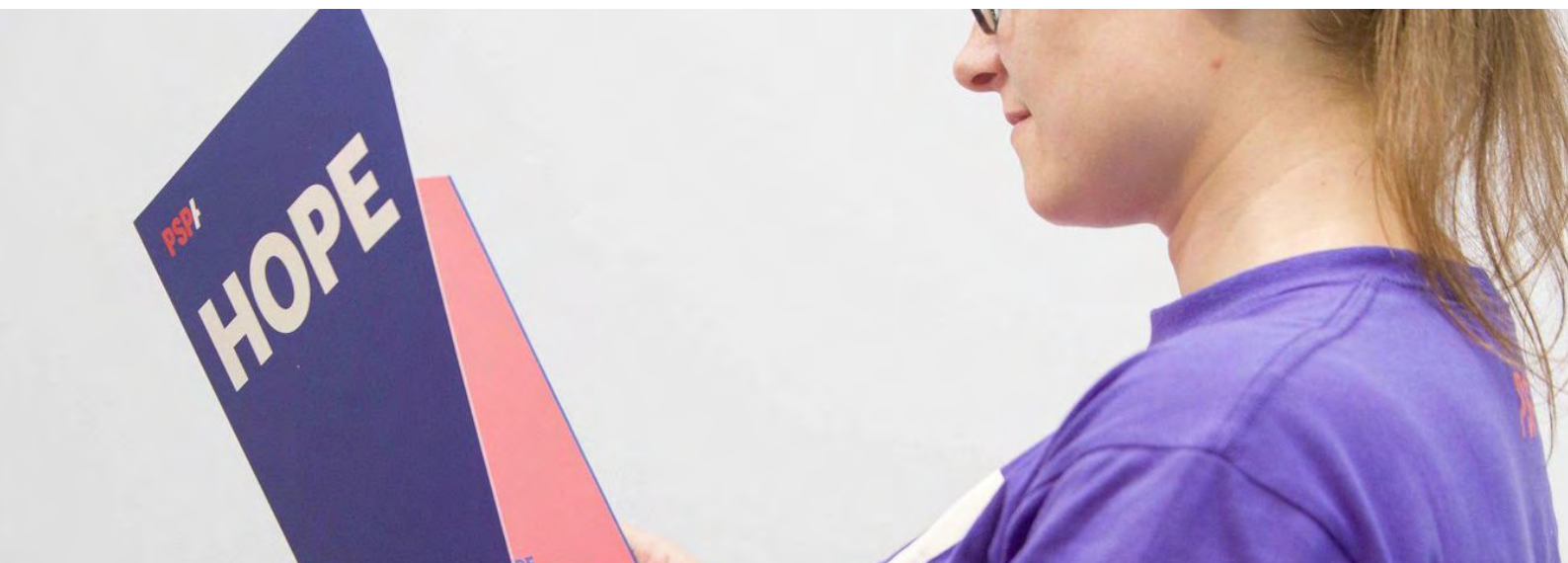
For our new Chief Executive there is enormous opportunity to deliver significant impact and to grow our profile and income. This is a time for us to drive the charity forward with confidence and ambition. You will be a visionary and strategic leader with a deep sense of social purpose and a track record 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 build a positive, inclusive and collaborative culture. Our life changing work relies upon the generosity of our supporters, donors and volunteers and you will be an experienced income generator with exceptional communication skills and the ability to leverage our position so that we can deliver even greater impact for those we serve.

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 reach even more 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 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 27 years ago, we have made significant progress in raising awareness and supporting people living with these devastating neurological conditions. Recent published research estimates there are 10,000 people living with PSP and CBD in the UK. Understanding and finding a cure for PSP & CBD would not only be a breakthrough for those with these conditions but will deepen our understanding of other brain conditions too, including Alzheimer's and Parkinson's.

Income averaged £1.3m in the three years to 2019 and despite 2020 being a much tougher year the charity still has a strong balance sheet. PSPA currently supports around 1800 people living with PSP, 300 people with CBD and a further 3000 people who are supporting someone with these conditions.

In 2013, PSPA created the UK National PSP Research Network, which brings together leading experts from many areas of biomedical research, including neuroimaging, clinical analysis, pathology and genetics. We also co-founded Promotus in 2019, as an international partnership with other patient advocacy organisations globally, to share information and research outcomes with a view to an eventual cure for PSP & CBD.

## 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 "junk protein" called tau builds up in 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** – it damages the brain centres that control eye movements.

**Palsy** – it causes weakness.

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 “junk protein” tau in certain parts of the brain, the classical clinical picture is 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.

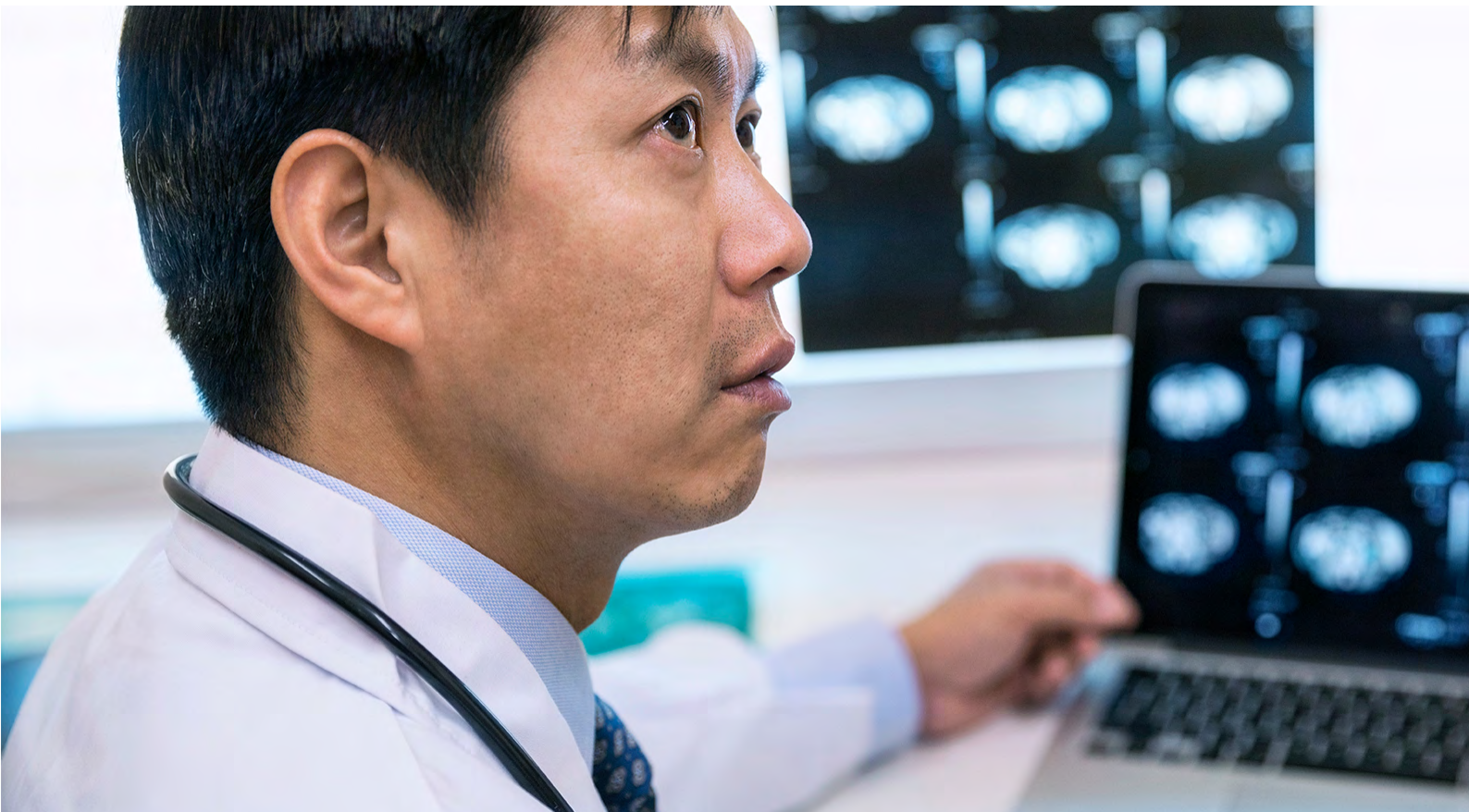
There are currently no treatments for CBD but there are a number of ways to help manage the symptoms and simple practical solutions that can help get around some of the problems people living with CBD experience. As with PSP, there are no simple tests or brain scans for CBD to help neurologists diagnose the condition. CBD is often initially misdiagnosed as a Stroke or Parkinson's disease.

## Our heritage and our future

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

The charity was set up 27 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. The three aims of the charity were to promote and sponsor research into the cause, treatment, and cure of PSP; to raise awareness among the general public; and to provide information and support across the UK for families affected.

Over the last ten years significant progress has been made with raised awareness and new treatments and trials, and there is optimism and positivity about the future. As we embark upon the next ten years with a new Chair and Chief Executive at the helm, PSPA is looking to build an even stronger identity to become recognised globally as a leader in coordinating the fight against PSP & CBD.



# 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.
- An inspiring and authentic individual who is passionate, confident and engaging, with a collaborative leadership style.
- A senior professional who will be the key proponent of the campaigning and influencing drive of the charity.

## 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.
- Champion, advocate for, create and maintain 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 with the Fundraising Manager, lead on the charity's income generation plan, proactively seeking out new partnerships and identifying funding 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.
- Manage the relationships with existing partners, ensuring compliance with current commitments and maximising opportunities for enhanced collaboration and funding.

### External representation

- Identify and generate productive strategic relationships with external stakeholders; work collaboratively with other patient organisations 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.

### Governance and financial management

- Work closely with our Board to ensure that all legal and regulatory responsibilities are carried out and 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.
- A proven track record of successful income generation and implementing growth strategies, ideally with direct experience of fundraising in the non-profit sector. Including generating leads, pipeline development and conversion.
- 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

<b>Salary</b>	Circa £70k
<b>Location</b>	The PSPA office is in Milton Keynes; we would want the CEO to be able to spend at least one day a week in the office.
<b>Pension</b>	Workplace Pension Scheme
<b>Annual leave</b>	28 days
<b>Working hours</b>	37.5 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 [juliet.taylor@starfishsearch.com](mailto:juliet.taylor@starfishsearch.com) or [juliet.brown@starfishsearch.com](mailto:juliet.brown@starfishsearch.com) and we will be happy to arrange a call.

To make an application, please go to <https://starfishsearch.com/jobs/pspa-ce/> 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.

Please ensure you have also completed and submitted the equal opportunities monitoring form. The information you provide will be treated as confidential and used for statistical purposes only. The form will not be treated as part of your application.

<b>Closing date</b>	9.00am Monday 21st June 2021
<b>Informal meetings with Starfish Search</b>	w/c 28th June 2021
<b>Agreement of the final shortlist</b>	w/c 5th July 2021
<b>Final panel interview event</b>	w/c 19th July 2021





