

Candidate pack for Chair, PSP Association



Introduction from the Board of Trustees

Dear Candidate,

Thank you for your interest in becoming our new Chair.

PSP Association (PSPA) are over 30 years old. With a strong leadership team, led by an ambitious Chief Executive, James Cusack, and with a balance sheet that will enable us to invest more ambitiously in the things that make a difference to our beneficiaries, this is a significant time to join as our new Chair as we look to grow our profile and impact further.

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 10,000 people alongside their families and carers across the UK 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.

You will bring your strategic reach, highly developed interpersonal skills and strong governance skills to support and develop the Board through a time of change and growth. We are looking for an experienced organisational board member or chair who has the skills, techniques, and intuition to support and guide a small team. We are proud of our inclusive and collaborative culture, and we are looking for an emotionally intelligent leader who can demonstrate a natural affinity with our mission.

Our life changing work relies upon the generosity of our supporters, strategic partners, donors and volunteers and you will possess exceptional communication and influencing skills and will be credible with research, clinical, care and patient communities.

If you are excited by the opportunity to join us and change people's lives now and in the future, we'd love to hear from you.

Best wishes,

Board of Trustees



PSPA

Candidate pack for 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. 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, including Alzheimer's Disease and Parkinson's Disease.

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.

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.

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 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. 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, 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.



Job description

Job title: Chair of the Board of Trustees

Key relationships: Trustees, CEO and Executive Leadership Team, stakeholder community

Role purpose:

The primary responsibility of the Chair is to ensure that the activities and plans of PSPA fulfil its charitable objects. The Chair provides leadership to the PSPA Board with prime responsibility for ensuring it has agreed priorities, appropriate structures, processes and a productive culture and has trustees and senior staff who are able to govern well and add value to the charity. The Trustee Board is responsible for setting the strategic aims, objectives and direction of PSPA, delegating day-to-day management to a Senior Leadership Team (SLT) led by the Chief Executive, and ensuring the long-term sustainability of the charity. The Chair's main role is to provide clear leadership to the Board; to demonstrate an ability to set the Board agenda, and lead trustees in playing a full role in the development and determination of the charity's strategy.

Main responsibilities:

In addition to those duties and responsibilities performed by all trustees, the Chair has a set of specific, additional accountabilities as follows:

- Lead the Board, providing clarity of vision to the Board in fulfilling its charitable objects and encouraging all trustees to contribute their skills, experience and opinions, creating a Board environment with strong working relationships and where challenge, scrutiny and diversity of perspectives are welcomed;
- Ensure that the Board of Trustees has the necessary and diverse range of skills, expertise and life experiences; that new Trustees are properly inducted, and that appropriate Board development and annual Board appraisal is undertaken;
- Provide support, stretch and guidance to the Chief Executive and their team;
- Ensure effective governance and efficient administration of the Charity and its trading subsidiary, and ensure financial stability and legal compliance within the Charity Commission's regulatory guidelines and within regulatory frameworks of the devolved administrations, as appropriate;
- Guide and oversee the approval of strategic plans and discussions on the strategic development of PSPA, ensuring that the Board has agreed strategic priorities;
- Lead in the annual appraisal of the Chief Executive, support her/him and delegate the day-to-day management of the Charity to the CEO and SLT;
- Build and maintain close relations between the Charity's various constituencies as needed, meet with senior key external stakeholder groups to promote PSPA and represent PSPA and its Board at functions and events;
- Chair Board meetings, liaise with the Chief Executive and Company Secretary, where appropriate, with the drafting of agendas and supporting papers for trustee meetings and ensure that business is covered efficiently and effectively in those meetings;
- Ensure, in liaison with the Company Secretary, that appropriate Board procedures, processes and controls are in place and are followed;
- Undergo an individual and Board performance appraisal, undertake evaluations of the performance of trustees and direct remedial actions where required;
- Safeguard the reputation of PSPA, upholding the values of the charity by example;
- Ensure that the organisation promotes diversity and inclusion for all its stakeholders;
- In moments of crisis, between full meetings of the Board, authorise action to be taken as necessary to protect the people, work and reputation of PSPA in furtherance of its charitable objects;
- Use her/his networks and connections to further PSPA and its aims.

Person specification

Knowledge and experience

- Strong knowledge of the principles of good governance and financial oversight, and the respective roles of the Board and Executive.
- Experience of strategic leadership in an organisation undergoing growth and change.
- Experience of working with executive teams to help set strategic direction and support delivery.
- Knowledgeable about Board development, ideally with experience of developing new Board members.
- Experience of influencing and engaging with a variety of stakeholders, e.g., staff, donors, volunteers, clinical, care, research, or patient communities.

Personal style and behaviours

- Values-led, visionary leadership, driven by a deep commitment to our mission.
- High emotional intelligence and empathy with the PSP and CBD community and their families and carers.
- Low ego leadership style with personal presence that garners trust and confidence.
- Collaborative in approach yet willing to offer challenge and stretch when needed.
- Brings a sense of perspective, sound judgement and capacity for self-reflection.
- Diplomatic style; happy to galvanise support personally for PSPA's work.
- A team player who enjoys working with others in a smaller organisational setting.

Skills and abilities

- Outstanding strategic leadership and board management skills.
- Mentoring or coaching skills and the ability to inspire and develop others.
- Highly skilled in persuading, influencing and negotiating.
- Exceptional communication and interpersonal skills.
- An agile strategic thinker.
- High intellectual capacity and credibility.
- Commercially and financially astute.



Terms of appointment

Term and remuneration

The Chair role is for one single term of 5 years; however Trustees may serve up to two consecutive terms of three years each.

This role is offered on a voluntary basis. All reasonable expenses incurred in the role are reimbursed.

Time commitment

The role requires up to 2 days per month. This includes:

- 4 Board meetings per year – 2 in person in Milton Keynes and 2 online
- Attendance at Finance and Risk Committee 5-6 meetings per year online, Research Committee 2 days a year
- Meetings with the CEO (in person and online)
- Representation of PSPA at key external events one-to-one meetings with trustees, and attendance at other ad hoc meetings as appropriate.

Location

Board meetings take place at the office in Milton Keynes and are a mix of in person and hybrid. We welcome applicants from across the United Kingdom and will reimburse travel expenses should this be required.

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 rebecca.oconnor@starfishsearch.com and we will be happy to arrange a call.

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

- Your CV (no more than three sides).
- A covering letter that sets out your motivation for the role and describes the specific experience you can bring to the appointment to support PSPA's aims.

Closing date: Friday 4th December 2026

Preliminary interviews with Starfish: w/c 14th December 2026

Interviews with PSPA: w/c 11th January 2027