



PSPA Research Strategy 2020-2025

The strategy comprises of **four strategic elements identified from the consultation with patients, carers, clinicians, researchers and organisations with a link to PSP and CBD.**

1. Prioritising PSPA Research

- Supporting new research ideas in a responsive manner
- Supporting five research themes and targeting research in areas of high priority which encompass:
 - Prevention and causes
 - Awareness and education
 - Improved diagnosis, reduced misdiagnosis
 - Drug discovery and targeted treatments for the underlying causes
 - Improved interventions for the treatment of the all the symptoms of the conditions

All five research themes should enable a patient to live the best they can with PSP and CBD

2. Research Stars of the Future

- Growing new talent and new expertise, and creating the “research stars of the future”
- Supporting the rising stars in research to become the academics of the future who will lead the way in finding treatments, improving diagnosis and care for people with PSP and CBD in the next few decades.

3. Patient Engagement in Research

- Supporting research which reflects patient views and priorities, and encouraging and enabling anyone who wants to engage with our Take Part in Research Programme, giving them a Patient and Carers Voices in Research.
- Educating members by working with local groups about PSP and CBD
- Supporting the helpline team in answering member enquiries and providing research information and answering scientific questions
- Working with pharmaceutical patient advocacy teams to encourage patient engagement in clinical trials

4. Communication, Collaboration and Change

- Communicating research – bringing research findings to the people affected by PSP and CBD, our supporters and funding partners
- Working with research institutions, charities, medical and health associations such as the Neurological Alliances, AMRC and ABN, and other overlapping health related charities to lobby government agencies and NHS commissioners for changes in clinical provision and pathways for people with PSP and CBD