

ACTION FOR BPAN

England & Wales · Charity number 1210529

Details

Status Registered

Legal form CIO

Registered 2024-10-17

Register [View on the Charity Commission register](#)

Contact

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Activities

Objects: THE OBJECTS OF THE CIO ARE TO PRESERVE AND PROTECT THE GOOD HEALTH OF THOSE SUFFERING FROM BETA PROPELLER PROTEIN-ASSOCIATED NEURODEGENERATION (BPAN) BY:-MAKING GRANTS TO VETTED MEDICAL PROFESSIONALS TO CARRY OUT RESEARCH FOR A CURE OR TREATMENT OF THE CONDITION AND TO PROVIDE SUPPORT TO CAREGIVERS OF THOSE WITH BETA-PROPELLER PROTEIN-ASSOCIATED NEURODEGENERATION (BPAN);PROVIDING USEFUL INFORMATION FROM UK BPAN SPECIALIST DOCTORS, SIGNPOSTING AND HELPING NAVIGATE THE SUPPORT AVAILABLE BY SHARING PERSONAL EXPERIENCES TO ENSURE THEY CAN ACCESS SERVICES THAT MAY BE BENEFICIAL TO THEM; ANDPROMOTING AWARENESS AND ADVANCE THE EDUCATION OF BETA-PROPELLER PROTEIN[1]ASSOCIATED NEURODEGENERATION (BPAN) FOR THE GENERAL PUBLIC AND HEALTH PROFESSIONALS USING A VARIETY OF DIFFERENT MEDIUMS.

Activities: Action for BPAN supports individuals with BPAN (Beta-Propeller Protein-Associated Neurodegeneration), a rare neurodegenerative disorder. We fundraise for research, raise awareness, and provide support to families affected by BPAN. Based in the UK and operating globally, we collaborate with medical professionals and communities to improve lives and advance treatments and cures for BPAN.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, The General Public/mankind

Geography

- Australia
- Canada
- France
- Germany
- Guernsey
- Isle Of Man
- Italy
- Jersey
- Netherlands
- Northern Ireland
- Scotland
- Spain
- Sweden
- Switzerland
- United States
- Throughout England And Wales

Trustees

Name	Role	Appointed
Kelly Ann Sayers Ms	Chair	2024-09-16
Nicole Harper		2024-09-16
Schalk Visser		2024-09-16
Susannah Kemmis		2024-09-16