



Esme's Umbrella

FOR EVERYONE WORKING FOR THE GREATER AWARENESS OF

Charles Bonnet Syndrome

CHARLES BONNET SYNDROME RESEARCH 2015-2023

**Funding sourced or co-funded by Esme's Umbrella
(Charity number 1197087)**

The world's first Charles Bonnet Syndrome research was led by Professor Dominic ffytche at King's College London. This produced the SHAPED report – <https://jnnp.bmj.com/content/91/5/512>

Think Sight Loss Think Charles Bonnet Syndrome 2019 - <https://discovery.ucl.ac.uk/id/eprint/10088653/1/2515841419895909.pdf>

An overview of psychological and social factors in CBS
<https://openaccess.city.ac.uk/id/eprint/27181/>

Trans-cranial direct current stimulation -
[Transcranial Direct Current Stimulation in the Treatment of Visual Hallucinations in Charles Bonnet Syndrome: A Randomized Placebo-Controlled Crossover Trial - PubMed \(nih.gov\)](#)

CBS proved in children and young adults
<https://bjo.bmj.com/content/early/2020/09/15/bjophthalmol-2020-317237>
[published 16th September 2020.](#)



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Stress and Isolation exacerbate Charles Bonnet Syndrome

- <https://bmjophth.bmj.com/content/6/1/e000670>

NEWCASTLE UNIVERSITY (2018-2020)

CBS research conducted by the team at Newcastle University – led by Professor John-Paul Taylor and Dr Kat da Silva Morgan in conjunction with Professor Dominic ffytche at King's College London

Dr Kat da Silva Morgan



Professor John-Paul Taylor



Part One investigated the difference in the brains of people with sight loss who develop CBS and those with sight loss for whom the condition plays no part in their lives.

[da Silva Morgan 101450388 eThesis.pdf \(ncl.ac.uk\)](#)

Funded by Fight for Sight, Esme's Umbrella, Thomas Pocklington Trust and National Eye Research Centre

Part Two explored the possibility of using Transcranial direct current stimulation to target specific areas of the brain in order to modulate its activity. In September 2022, a landmark study was published.



Led by Dr Kat da Silva Morgan, who is one of Esme's Research Fellows and Professor John-Paul Taylor, the study shows that the occurrence of CBS hallucinations can be significantly reduced by the use of a non-invasive electrical brain stimulation technique that makes the visual parts of the brain less excitable. This is the first-ever study of CBS treatment in a clinical trial setting using a placebo and is the best possible evidence that a treatment works. What we need now is investment to optimise the treatment and develop it into something that could be widely adopted by the NHS and given to people in their homes.

[Transcranial Direct Current Stimulation in the Treatment of Visual Hallucinations in Charles Bonnet Syndrome: A Randomized Placebo-Controlled Crossover Trial - PubMed \(nih.gov\)](#)

<https://pubmed.ncbi.nlm.nih.gov/35817197>

Funded by The Macular Society

MOORFIELDS/UNIVERSITY COLLEGE LONDON

Following the exacerbation of patients' episodes of CBS during COVID-19's induced lockdown, Professor Mariya Moosajee led an investigation 'Understanding and mitigating the impact of social isolation on Charles Bonnet Syndrome amongst the sight impaired'.

Published in BMJ Open Ophthalmology in 2021 - <https://bmjophth.bmj.com/content/6/1/e000670>

Funded by the Wellcome Trust

MOORFIELDS/OXFORD EYE HOSPITAL/CAMBRIDGE

Led by Professor Moosajee (Moorfields) and Professor Susie Downes (Oxford), this will be a mini-CBS prevalence study across different specialities.



UNIVERSITY OF OXFORD

A research team from the Nuffield Department of Clinical Neurosciences at the University of Oxford – led by Professor Holly Bridge and Dr Jasleen Jolly - will use MRI scans to compare the brains of people with and without Charles Bonnet syndrome to look at how they differ.

Professor Holly Bridge

Professor Holly Bridge said: “In the healthy visual system the eye provides input to a large area of the brain that allow us to see the world. There are specialised brain regions responsible for the processing of faces, objects, motion and colour. When the eye is no longer working these parts of the brain lose their input and we think this can lead to abnormal activity. In particular we will use a special type of MRI scan in this study to measure



the levels of chemicals in the visual areas of the brain to see whether they are abnormal in CBS, leading to the hallucinations.”

Not all people with eye disease and vision loss develop CBS, so we will use magnetic resonance imaging (MRI) to compare the brains of people with and without the condition. In particular we are interested in measuring the levels of chemicals in the visual areas of the brain to see whether they are disrupted in CBS, leading to the hallucinations. We can also measure how the different areas of the visual brain are connected together and see whether this is altered in CBS, perhaps with increases in the strength of connection between specialised areas.

The study will provide insight into the role of the brain in generating CBS hallucinations, helping us to design a larger study and eventually to test whether there are interventions to help improve the condition.

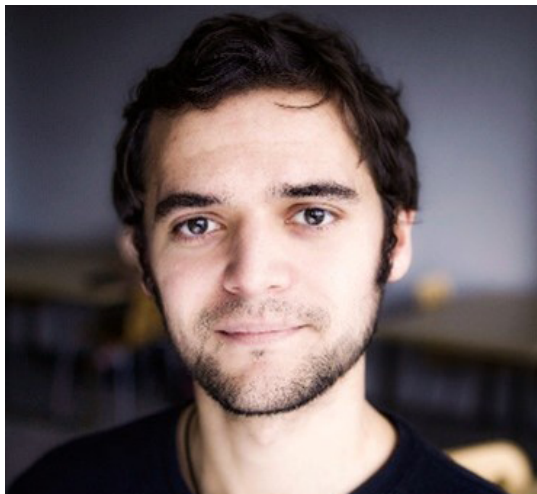
The research is co-funded by Esme's Umbrella, Blind Veterans, NIHR, The Royal Society, The College of Optometrists



CARDIFF UNIVERSITY

Researchers at Cardiff University are embarking on a new study to investigate whether peripheral (side) vision is more 'suggestible' than central vision.

The team – led by Dr Matt J. Dunn from the School of Optometry and Vision Sciences – will use a novel technique to induce controlled visual hallucinations in the lab. They are particularly interested in whether these lab-induced hallucinations more readily occur when targeted to the visual periphery (side vision) than straight-ahead. The team hope to gain a better understanding of how the brain interprets visual signals from different parts of the retina, which may help to explain the origins of Charles Bonnet Syndrome.



Dr Dunn said: "Although many people with Charles Bonnet Syndrome report hallucinations that appear to be located in the central visual field, we know that central vision is almost always damaged in these patients, so we are interested in where those signals might originate from. We hope to gain a better understanding of the role of expectation on visual perception in fully-sighted individuals, in order to provide a

plausible explanation as to why Charles Bonnet Syndrome and other hallucinatory disorders occur in the first place".

In this study we are testing a hypothesis that following long-term central vision loss, patients with Charles Bonnet Syndrome pay more attention to their peripheral vision, which is more reliant on expectation and previous experience than central vision, and therefore prone to hallucinatory experiences. We will use a novel lab-based test to measure a person's reliance on prior expectation when generating visual percepts. This test will be applied to fully-sighted people using visual stimuli shown to both central and peripheral visual locations. Our aim is to determine whether peripheral vision is more suggestible than central vision."

The research is co-funded by Esme's Umbrella, Fight for Sight and Health and Care Research Wales.



MOORFIELDS/UCL AND GREAT ORMOND STREET HOSPITALS

This is in two parts.

Led by Professor Mariya Moosajee and Dr Lee Jones, the team conducted a prevalence study of paediatric ophthalmology clinics to ascertain how common CBS in children. Prevalence has been proved.

The study will then look at how CBS affects the lives of the children and the family.

Part one - <https://bjo.bmj.com/content/early/2020/09/15/bjophthalmol-2020-317237> published 16th September 2020.

Funded by Thomas Pocklington Trust

MEDICAL DETECTION DOGS

Following the revelation that, at least one, guide dog is warning her owner before a CBS episode begins, The Medical Detection Dogs are investigating what change in the odour of the human body is being detected by the dog and how long before the CBS episode begins. This may lead to more research into the chemicals of the brain.



Judith Potts with Medical Detection Dog, Eliza, who is investigating CBS.

Funded by Medical Detection Dogs

MANCHESTER UNIVERSITY

Katharine Fisher, a PhD student at the University of Manchester's School of Health Studies, is conducting an exploration of how we can prevent people with CBS from falling. This is a very common occurrence because, even if the person is well aware that the hallucination is not real, the nature of the image will, inevitably, induce a physical reaction – and over-balancing or falling over an item of furniture is the result.

This may entail a trip to hospital or the GP, with a decision to make – to confide or not to confide. Even if the patient knows that CBS is present, confiding to a doctor – who probably has no idea about CBS - about the tiger/snake/person which caused the fall might result in a mis-diagnosis and a trip down the mental health route. This causes more distress to the patient and wastes precious NHS resources.

Katherine's PhD fees are funded by Thomas Pocklington Trust

UNIVERSITY COLLEGE DUBLIN

The first CBS prevalence study will be conducted by Fighting Blindness and University College Dublin in the autumn of 2020/beginning of 2021 – which will lead to a wider piece of research.

ANGLIA RUSKIN UNIVERSITY/CRABBE LAB CITY UNIVERSITY, LONDON

Led by Dr Jasleen Jolly, this study will use EEG to better understand brain activity during the hallucinations.





NEW CBS RESEARCHER – SMALL GRANT AWARD

In May 2022, Fight for Sight – on behalf of Esme's Umbrella – put out a call for another CBS researcher. This was won by Dr Tamsin Callaghan from City University, London, who will study 'The impact of educational tools on hallucinations in Charles Bonnet Syndrome'.

BRAVO VICTOR

In February 2023, the Minister for Veterans' Affairs, Rt Hon Johnny Mercer, announced a substantial grant had been awarded to Bravo Victor – working with Esme's Umbrella and Moorfields' Eye Hospital – to 'improve understanding of visual hallucinations among military veterans and refine management strategies to ensure individuals receive an accurate diagnosis and appropriate healthcare'. The research will be led by Professor Renata Gomes and Dr Lee Jones, with Professor Mariya Moosajee.

This means that CBS has been acknowledged by the British Government.



Dr Lee Jones
Thomas Pocklington Fellow
BRAVO VICTOR

Prof Renata Gomes
Chief Scientific Officer
BRAVO VICTOR



Dr Lee Jones presented this Abstract at the ARVO Conference in the USA in 2023.

[Clinical features and practice patterns in managing patients with Charles Bonnet syndrome and characterising psychological outcomes of visual hallucinations in military veterans | IOVS | ARVO Journals](#)

Young researchers are becoming very interested in CBS research. We assume this is because CBS now has its own coding in ICD 11, achieved by Judith Potts with the help of Professor Andrew Dick (UK) and Dr August Colenbrander (USA).





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