**JUDITH POTTS**

**Founder of Esme’s Umbrella**

**Campaign to raise awareness of Charles Bonnet Syndrome (CBS)**

Esme’s Umbrella is the UK Campaign to raise awareness of Charles Bonnet Syndrome and funds for research into this distressing condition. I launched it at the House of Commons three years ago in memory of my mother, for whom CBS tormented her final years.

In the last three years I have written countless articles for newspapers and magazines about CBS, how it affects the patient’s quality of life and how the condition has been misunderstood and dismissed much too lightly as ‘just a side effect of sight loss’. It is so much more than that, particularly if the patient has received no warning about CBS’s silent, vivid, visual hallucinations. The fear and misapprehension that these images are due to a mental health issue prevent people from confiding in anyone. GPs and Hospital Doctors mis-diagnose – purely because of lack of awareness of CBS – and send the patient down the mental health pathway, which wastes the precious resources of the NHS.

I have found great support from the ophthalmology/optometry world and have spoken at meetings large and small - from the President’s session at the Royal College of Ophthalmology’s Congress to eye disease support groups.

Last November, I hosted the world’s first Charles Bonnet Syndrome Patient Day at Moorfields to coincide with the official Charles Bonnet Syndrome Awareness Day on 16th November – and there is another planned for this year. The first Information Day is scheduled for April 2019 in York, with more being planned for other parts of the UK.

In order to offer some support for people with CBS, their families and friends, I have launched a series of Esme Room Support Groups. Hosted by local low vision charities, these groups gather together to exchange CBS experiences and coping strategies. Here they find the only real treatment available – reassurance and camaraderie.

Thanks to Fight for Sight, The Thomas Pocklington Trust and the National Eye Research Centre, Esme’s Umbrella has a researcher at Newcastle University, who is comparing the brains of people with sight loss and CBS against those with sight loss who never develop the condition. If we can identify the difference, there may be a chance to develop a non-medication, non-invasive treatment to dispel the hallucinations. I hope that, this year, the call from Fight for Sight will be answered again. There is so much more work to be done – medical, as well as into prevalence and social research. It is estimated that there are 1 million people of all ages in the UK living with CBS – not everyone will have multiple or disturbing hallucinations, but the frequent appearance of a small child, frogs flowing from the tap or a floating staircase can impact negatively on daily life at any age.

To my astonishment, Jane Macnaughton nominated me for the Low Vision Award from Optical Awards 2019, which was incredibly gratifying and I felt extremely honoured when I made the short list. This was proof that my work is being noticed, appreciated and taken seriously by the sector.

I have been in contact with Dr August Colenbrander at Smith-Kettlewell, who is working with Professor Andrew Dick on the ophthalmology section of The World Health Organisation’s ICD-11. It is hoped that CBS will have its own code and, if this happens, there will be no excuses for leaving people in a frightening world of hallucinations which can cause them to become house-bound, stop eating and drinking or contemplate suicide.

Research into CBS began in the 1990’s when Dr Dominic ffytche of King’s London began his programme, looking into visual hallucinations caused by Parkinson’s, Lewy Body Dementia and CBS – a mere 250 years after Charles Bonnet first documented the condition! His work continues and he has been joined by my researcher in Newcastle but there is no other research happening in any other country. This is the perfect time for the ophthalmology/optometry sector to join forces and persuade the NHS to take the lead and create a proper pathway for diagnosis, treatment and support.

Meanwhile, I have other small projects in the pipeline, which will help to discover more about this disturbing and extremely common condition. Esme’s Umbrella is just me and I would appeal to anyone with time and a passion to help those who live with CBS, to contact me. I need Ambassadors to carry the message across the whole of the UK, as well as researchers of all types who would be interested in gathering the data which funders seek before they offer to back a large campaign or research project.

Thank you.