



PO Box 2592, Indian Trail, NC 28079 (704)389.0160

Dear Dr. / Health Care Provider,

Have you heard of Charles Bonnet Syndrome (CBS)? I am a patient/family member/caregiver/friend who lives with Charles Bonnet Syndrome. Unfortunately, few doctors are aware of this condition, and individuals with CBS are being misdiagnosed and ushered down the mental health route at an astounding rate. This is not only a waste of medical resources but also very distressing for the patient and their families.

Charles Bonnet Syndrome is a physiological condition that develops when an individual loses visual acuity or becomes blind after having vision. CBS causes vivid, silent visual hallucinations with absolutely no warning. There is no auditory or tactile component. These hallucinations can range from simplistic to disturbing. Charles Bonnet Syndrome can affect individuals of any age, ethnic background, or gender, lifestyle or socioeconomic status.

CBS has been assigned an ICD code by the World Health Organization (ICD-11-9D56) and has been recognized as a physiological condition in its own right. It is NOT a mental health condition, nor is it rare. The CDC estimates that there are 20 million people in the US diagnosed as legally blind. It is estimated that 1 in every 3 of these individuals is living with CBS. To properly diagnose and treat this condition, it is crucial that the medical community be educated about CBS. Currently, billing codes R44.1 and H53.16.8 are used by doctors treating CBS as reimbursable codes for insurance and Medicare/Medicaid. However, these codes do not designate CBS verbatim, which is necessary for diagnosis, treatment plans, and research.

Once the medical community understands and recognizes Charles Bonnet Syndrome, we can reduce the number of misdiagnoses individuals with CBS often receive, re-evaluate those who have been misdiagnosed, begin much-needed research, discover and administer correct and viable treatments for those individuals coping with CBS, connect people with CBS to community resources, and, most importantly; help these individuals to live with dignity, inclusion, and peace of mind while enhancing and preserving their quality of life.

Please take a moment to learn more about Charles Bonnet Syndrome at Marycarmelslight.com, Charlesbonnet.com, Esmesumbrella.com, and The Charles Bonnet Podcast on all your favorite podcast applications. You can learn about CBS, coping mechanisms, current research, and support groups there. If you have any questions or want more information, please do not hesitate to contact Dr. Gary Cusick at 502.439.0398 or Mary Carmel's Light at 704.389.0160.

Thank you for taking the time to understand what this patient/family member/caregiver is experiencing and being mindful that it may be Charles Bonnet Syndrome.

Respectfully,

Dr. Gary Cusick

Education & Research Specialist

502.439.0398

Mary Carmel's Light.....*empowering people living with Charles Bonnet Syndrome* 02.16.26