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FEATURED

Siblings carry on Mary Carmel's 'intelligent' light despite hallucinations

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Kevin and Eva Potts honored their mother by starting an advocacy non-profit, Mary Carmel's Light, which touches on subjects relating to vision.

Michael Wayne O'Neill/EJ



INDIAN TRAIL, N.C. -- Just as she was starting to recover, Mary Carmel McCoy's life did not end well after six decades of experiencing hallucinations.

After Mary Carmel's passing in 2020 at the age of 87, her children -- Eva Potts and Kevin Potts -- started a non-profit in her honor to make the condition she suffered from, Charles Bonnet Syndrome (CBS), better known across the country.

Mary Carmel's Light is a 501(c)(3) nonprofit organization dedicated to supporting individuals with low vision or onset blindness affected by CBS, which is a condition where one sees things that are not real.

"We offer support groups every week," Eva Potts said. "We have an active helpline that operates 24-7 or we're able to help people that are in crisis or that are just trying to figure out what's going on with them when they start to experience Charles Bonnet Syndrome."

The Potts siblings are on the move helping people navigate CBS, which is often misdiagnosed. They have done two continuing education programs, one in North Carolina and one in Florida.

They are getting ready to do a continuing virtual education meeting with the New York Commission for the Blind, which will help them expand their efforts to recognize CBS.

Eva and Kevin spent the majority of their free time in the past caring for Mary Carmel, who they called a mother with a "intelligent, outspoken, quick-witted, and a human sponge" mind "that absorbed everything she experienced," according to their website, <https://marycarmelslight.com/mary-carmel/>.

"We didn't know what was going on," Kevin Potts said. "Our mother was just having hallucinations that were quite traumatic for her for quite a while. She wasn't crazy but it took us a really long time to figure out what (CBS) was because there is no information on it; nothing was being done about it. It wasn't until it was discovered through extensive -- seriously extensive -- Google searches by all of us. Our Aunt Rosemary, at one point, actually found it, that it was Charles Bonnet by the definition."

After taking it to her doctors, Eva connected with Dr. Gary Cusick, who is now one of the board members of Mary Carmel's Light. Cusick was with the Louisville Services for the Blind at the time when Eva was searching for answers for Mary Carmel.

The siblings believed Mary Carmel's hallucinations were caused by CBS, but she was misdiagnosed.

Mary's hallucinations would range from innocuous to extremely disturbing. She experienced patterns, large print, and text on what she imagined to be the walls in her room.

Mary Carmel lost her eyesight in the 1960s due to receiving amounts of Prednisone to treat Immune Thrombocytopenic Purpura (ITP), characterized by low platelet counts that can lead to bleeding in the eye or optic nerve. There was no effective treatment for ITP and it cost her a significant portion of her visual acuity.

According to the non-profit's website, "she saw many people all the time. The people she would see could be pleasant to downright scary. She saw Nazi soldiers, children in period clothing, and what she thought were burglars or thieves. Sometimes she saw bugs on her food or her clothing. She saw parades of clowns, people laughing at her, funeral processions."

On the outside, Mary Carmel loved to write, read the local newspaper, read every page of the Webster Dictionary, and work on crossword puzzles. She wrote poems about and for every person she loved. She wrote about her pain, anxiety, fears, triumphs, and the triumphs of those she loved.

Scott Keziah is a life counselor who worked with Mary Carmel on her sight. He said meeting Mary Carmel was one of the most profound moments of his career.

"I said to Mary 'I want you to see me,' and then she responded with 'how do we do this?' I asked if she would give me her hands and trust me," Keziah said. "She reached out with her hands; I leaned forward and placed them on my face. I asked Mary to explore my face until she was able to create an image of me in her mind. When she was finished, she said, 'I see you now' and 'stop wearing cologne when you come to see me.'"

Eva and Kevin also discovered how many people were being diagnosed with dementia and schizophrenia who lived with CBS.

The solution? They found coping mechanisms for Mary Carmel dealing her hallucinations.

The two also want to encourage more research on the effects coming from CBS and a course of action.

“For research to begin, we need for a doctor that belongs to the AMA to fill out the application with the American Medical Association and they have to be a member because the AMA owns the application for what's called a CPT code,” Eva Potts said. “That's what every diagnosis has for a doctor to be able to bill and be reimbursed for services. If you don't have it, you're not going to get diagnosed. Treatment plans will not begin and research will not begin, so we need that CPT code.”

Eva Potts said she wanted to thank Keziah, Martha Smith Allen, Bryan Morales, Cindy Grano, Dana Draa, Dequan Starnes, and Ulunda Baker for helping the siblings see potential in advocating for CBS.

In the meantime, Eva said CBS is not painful but can be a unique challenge to face.

“Visual loss is a horrible journey to be on,” Eva said. “When Charles Bonnet (Syndrome) comes along and holds hands with it, it makes that challenge of navigating visual loss 10 times harder because the focus seems to shift from dealing with your visual loss to dealing with Charles Bonnet, because it's all consuming.”

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