

January 20, 2025

I am writing to support research to cure Blue Cone Monochromacy (BCM), a disease that has made my life harder for 75 years. I am not asking for sympathy; I am asking for help to cure those who have this disease and to prevent others from getting it.

Let me explain some of how BCM makes life harder for me now and how it did along the way.

First let me describe how I see the world. I am extremely myopic and light sensitive. I have to hold printed material very close to read (literally a couple of inches from my face) ...and then, only if it is of adequate size, with high contrast, and in a narrow range of illumination. I cannot read print in sunlight. As a lay pastor, I preach from text printed in very large and bold 33 point Arial Black. My color vision is limited to blue, green, black, and grey. Everything else is in terms of those colors. My notion of those colors is very broad. For example, my green includes orange, brown, and beige. My notion of blue includes pink, purple, and violet. My 'black' includes burgundy and several reds.

I have always had to depend on others to match clothes, to tell when food was properly cooked, and to decode color cues. Color cues abound. From traffic lights to weather maps to on-sale coding, the world is constructed to accommodate those with normal color vision, not those with BCM. Computer screens have all sorts of color cues, not to mention color palettes that make web pages difficult to navigate.

BCM has complicated my education from grade school through graduate school. Poor vision often comes with very poor penmanship. Reasonable accommodation of the needs of people with disabilities may be the law of the land, but too many teachers are insensitive to such needs, especially when the person doesn't "look like they have a problem."

BCM complicates social development. Poor vision made a variety of sports hazardous to me, but made much of my childhood socially awkward and isolating. As an adult at a dinner party with people I just met, I was once asked, "You don't golf, fish, hunt, or play ball ...what good are you?"

All my life, people have expected me to see their facial expressions and hand gestures, even people who know that I am legally blind. This has often led people to underestimate my intelligence or to judge my social skills as lacking. Imagine your self-esteem being constantly challenged all of your life. Imagine growing up with most of the world seeing you as damaged goods, not worth considering for hiring or dating or befriending.

Poor vision and odd color vision make cell phones, tablets, and computers difficult to navigate. Even when you can enlarge print size, apps are not configured to accommodate that adaptation. Yes, there are laws and standards, but they are routinely ignored ...as are complaints to store headquarters.

BCM reduces independence. We treasure our freedoms, but freedom for those with BCM, is attenuated. Even at my eye doctor's office, I am regularly presented small print forms that I cannot read or complete without assistance ...and the new ones on line are no better, because they are designed to look slick, with legibility given short shrift.

BCM prevents driving, the major key to independence from age sixteen on. Not being able to drive limits where you can live or work. Imagine yourself as a teenager or young adult trying to get a date. We live in a car-dependent society. Just observe the number of TV ads for motor vehicles and their accoutrements. For a week or two, every time you jump into your car, ask yourself, "How would I do this if I couldn't drive?" Once in a while, someone would give you a ride (knowing you could return the favor), but no one wants to be your chauffeur.

Some may point to the accomplishments of people with BCM as an excuse to give up on a cure. I was blessed to have parents who did not devalue me because of my disability. In my three decades as the psychologist for the North Carolina Division of Services for the Blind, I met many, many people whose families regularly dissed and discouraged them because of their disability. I managed to make the highest SAT score in my public high school, graduate from Davidson College, and earn a Masters' and Ph. D. in psychology, but far too many people have their education truncated due to lack of access to accommodations to this rare disease. I have managed to marry and raise children, but far too many find the challenges of seeing so differently overwhelming.

Therefore, I urge you to fund research to cure and/or prevent BCM, a disease no one should ever have to live with.

Sincerely,  
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