CCHS is a rare disorder that affects females and males in equal numbers. Though the mutation is already present before birth, in milder cases the diagnosis may be missed until after the newborn period. Some affected individuals will not be identified until after receiving sedation, anesthesia, or anti-seizure medications, making it especially important to educate health care personnel about CCHS and to have a high index of suspicion for considering a diagnosis of CCHS. As of 2013, more than 1,000 cases are known worldwide. The birth prevalence of CCHS has been extrapolated from incidence figures and general birth rates, but the true prevalence is unknown as culturally diverse large population based studies have not been reported. Because the milder cases of CCHS may go unrecognized or misdiagnosed, it is difficult to estimate the true frequency of CCHS in the general population, though the anticipation is far greater than the current estimate.