

Supporting CDKL5



A survey of parents of children with cortical or cerebral visual impairment. Journal of Visual Impairment and Blindness 2010.

This study summarises the results of a survey of 80 parents who have children with Cortical or Cerebral Visual Impairment (CVI). The various aetiologies (causes) are reviewed along with rehabilitation and intervention strategies. The most effective rehabilitation is said to be that which involves parents and other family members. Motion, particularly of a coloured object is the most important factor in improving the visual response. The survey also looks at 3 issues - how do parents receive the diagnosis of CVI, what educational support do children with CVI receive, and what do parents of children with CVI feel about the support they and their children receive.

Note - This article has been written by parents of children with Cortical Visual Impairment (CVI) . This is not something that we read so much about in CDKL5 articles, as the focus tends to be on seizures, developmental delay and mobility. However, children with CDKL5 certainly do suffer from CVI and although this article covers a broad spectrum of issues, many are relevant to us which I think is very helpful.