

ABSTRACT.

Retinoblastoma is an aggressive eye cancer of infancy and childhood. Survival and the chance of saving vision depend on severity of disease at presentation. Retinoblastoma was the first tumour to draw attention to the genetic aetiology of cancer. Despite good understanding of its aetiology, mortality from retinoblastoma is about 70% in countries of low and middle income, where most affected children live. Poor public and medical awareness, and an absence of rigorous clinical trials to assess innovative treatments impede progress. Worldwide, most of the estimated 9000 newly diagnosed patients every year will die. However, global digital communications present opportunities to optimise standards of care for children and families affected by this rare and often devastating cancer. Parents are now leading the effort for widespread awareness of the danger of leucocoria. Genome-level technologies could make genetic testing a reality for every family affected by retinoblastoma. Best-practice guidelines, online sharing of pathological images, point-of-care data entry, multidisciplinary research, and clinical trials can reduce mortality. Most importantly, active participation of survivors and families will ensure that the whole wellbeing of the child is prioritised in any treatment plan.