

## INTERNATIONAL OPHTHALMOLOGY

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**Can National Retinoblastoma Strategies optimize global care?**

**Brenda L. Gallie, Peggy Gronsdahl, White Abby, Kahaki Kimani, Malipatna Ashwin, Helen Dimaras, Nataly Weizblit**

**Purpose:** Current science and state-of-the-art care for children with retinoblastoma is available to only 8% of the children affected world wide, which achieves 98% cure. Globally, the cure rate may be 30%. We are testing regional capacity building as a method to improve cure rates.

**Methods:** National Retinoblastoma Strategies (NRbS) for Canada, Kenya and India are developed collaboratively by multidisciplinary national teams. Guidelines, on-line registries and public awareness campaigns are core elements.

**Results:** The Canadian NRBS with broad representation including health professionals, parents and volunteers, is developing Best Practice Guidelines through regular national meetings and focus groups. A retinoblastoma-specific online database supports care and will be deployed for regular national tumor board discussion with participation of all involved with an individual child. The Kenyan NRBS is first targeting awareness and coordination of pathology review of enucleated eyes to effectively allocate resources to treat extraocular disease. The first working meeting of the Kenyan NRBS is booked for September 08. The Indian Retinoblastoma Working Group is prioritizing a national online registry in order to determine stage of diagnosis, treatments available and outcome as a basis for the Indian NRBS. These NRBS models reflect a broad range of care issues and potential solutions. The number of new annual diagnoses ranges from 24 (Canada), to 90 (Kenya), to 1600 (India); major issues are vision salvage (Canada), extraocular disease (Kenya) and access to care (India); large distance to travel for care affects families in all these countries. In each country, registries including all known children with retinoblastoma prospectively will facilitate measurement of impact of interventions.

**Conclusions:** Tools and processes modeled for NRBS in these diverse countries may be useful for other nations seeking to optimize care for retinoblastoma children.