

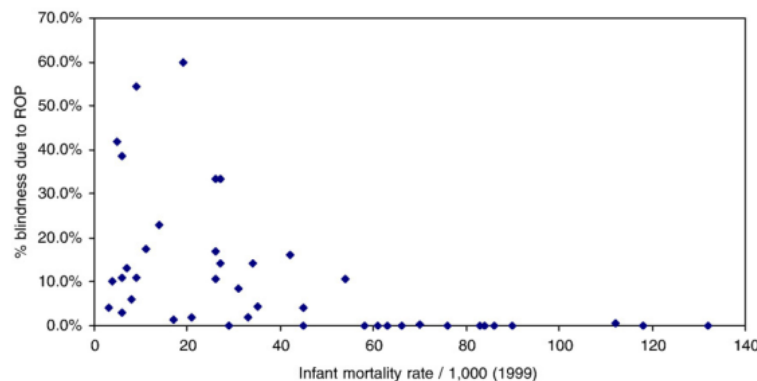
## Control of visual loss from retinopathy of prematurity in low and middle income countries

Retinopathy of prematurity (ROP) is a potentially blinding eye condition which affects infants born preterm (Hellstrom 2013; Chan-Ling, 2017). ROP is a major cause of blindness in children in many middle income countries (Gilbert, 2005) and is becoming an increasingly important cause in low and low-middle income countries as neonatal services expand and more preterm babies survive (Azad, 2016, Dutta, 2016). Recent estimates suggest that in the year 2010, 20,000 preterm infants become blind from ROP, and a further 12,300 survived visually impaired (Blencowe, 2013). All regions of the world are now affected. This study also estimated that 848,300 (range 838,400–924,700) preterm infants survive neonatal care and need to be screened, and 53,800 (range 28,800–85,000) infants need urgent treatment every year. Currently only around half of these infants are treated due to lack of services for screening and treatment. Once vision has been lost it cannot usually be restored.

ROP was first described over 70 years ago and the risk factors are well known. These include low gestational age and birth weight, inadequately monitored supplemental oxygen from immediately after birth, infection and failure to gain weight after birth. Pathogenic mechanisms are also better understood (Hartnett, 2015). Clinical trials have also clearly demonstrated that urgent laser treatment for the sight-threatening stages of ROP is very effective at preserving vision (Good, 2004). Blindness from ROP is, therefore, potentially avoidable in the majority of cases.

Studies show that countries with infant mortality rates (IMRs) in the range 9-60/1000 live births are the most affected (Figure 1)(Gilbert, 1997). In countries with high IMRs, most preterm infants do not survive. At the other end of the spectrum, countries with very low IMRs have low rates of ROP blindness as neonatal care services are of high quality and ROP screening and treatment services are available.

Figure 1. Proportion of blindness due to ROP, by infant mortality rate for the year 1999.



### The Impact

Blindness from ROP has economic, legal and social implications for affected children and their families, governments and civil society. For example, in India and South Africa there have recently been several very large medical negligence cases. Providing services for the prevention, detection and treatment of ROP is, therefore, financially and legally prudent.

A recent study from India, in which parents of ROP blind children were interviewed, powerfully illustrated the impact on families. Many parents experienced social isolation and most were concerned about the future of their child. Most had borrowed money or sold assets to pay for treatment, and several marriages had come under intolerable strain (Kulkarni, 2017).

### **Strategies for control**

- Prevention of preterm birth, which is challenging, but could include regulation of assisted fertilization practices, by limiting the number of fertilized embryos implanted (Janvier, 2011);
- Antenatal steroids for threatened preterm deliveries, which reduces many of the complications of preterm birth, including ROP (Travers, 2017);
- High quality neonatal care for preterm infants from immediately after birth, to control the known risk factors;
- High coverage of weekly ROP screening by ophthalmologists in neonatal units, or in eye units for babies who have been discharged from neonatal care, to detect infants with the sight-threatening stages. Screening can also be undertaken by neonatal nurses or trained technicians using wide-field imaging systems, supported by an ROP expert ophthalmologist (Chan-Ling, 2017)
- Urgent laser treatment of sight-threatening ROP by skilled ophthalmologists (Chan-Ling, 2017);
- Long term follow up to detect and manage the eye complications of preterm birth and ROP (Vijayalakshmi, 2016)
- Empowering community health workers to ensure mothers threatening preterm delivery give birth in facilities with a neonatal unit, with counselling about the benefits of antenatal steroids. Counselling mothers about the importance of screening for ROP and long term follow up.
- Strengthen at least one tertiary eye care department in each region/province as an ROP centre of excellence (Rani, 2016)

### **Policy framework**

Control of blindness from ROP needs to be owned and led by those responsible for newborn health, working in collaboration with eye care providers.

- Policies for the prevention, detection and treatment of ROP are needed, where the costs of screening and treatment are covered by government policies and/or health insurance
- National Guidelines need to be developed, which reflect the population of infants at risk, and which take account of the resources available, developed by Ministries of Health and relevant experts (Gilbert, 2016).
- National legislation mandating eye examination of all preterm infants for ROP and to regulate assisted fertilization practices
- National data collection and health management information systems for newborn care include screening for ROP, with systems for monitoring coverage

In a recent study in 10 countries in Latin America, higher screening coverage (95% of eligible infants were screened) was associated with having three or all four of the policies above in place; countries which had only one or two in place had a screening coverage of approximately one third of eligible infants (Arnesen, 2016).

### **Building capacities**

- Pre-service and in-service training curricula for nurses, paediatricians and neonatologists should include relevant aspects of ROP control
- Ophthalmology residency programmes should include ROP, and all retinal fellowships should include competencies in ROP screening and treatment

### **Costs and benefits of scaling up services for ROP**

A recent study in Brazil estimated that the incremental cost of integrating screening and treatment for ROP was less than 1% of the overall cost of providing neonatal care (Zin, 2014).

A study in Mexico and the USA estimated the costs to families of raising a blind child, and the lost productivity of carers and ROP blind individuals. These costs were considerable in both countries: in Mexico and the USA the incremental net annual monetary benefit of providing a service to prevent blindness from ROP was \$206,574,333 and \$205,906,959 respectively (Rothschild, 2016).

### **On the horizon**

New wide-field imaging systems are being developed at lower cost. Having an ROP imaging system on essential equipment lists would enable members of the neonatal team to screen for ROP, at a time that is convenient, so improving efficiency and effectiveness particularly for infants who require screening after discharge from the neonatal unit (Gilbert, 2016). Retinal imaging can also detect other serious conditions, such as intrauterine infection.

Intravitreal injection of Anti-VEGF agents for the treatment of ROP holds promise for the future, once the optimal agent, dose and ocular and systemic safety profiles have been established (Yonekawa, 2017).

### **Global policies**

The WHO/UNICEF initiative Every Newborn: An Action Plan to End Preventable Deaths, states that “a healthy society is one in which women and adolescent girls, newborns and children survive and thrive.” (WHO, 2014) The same applies to children who are born preterm.

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