

Role of Retinopathy of Prematurity (ROP) Tertiary Centers of Excellence in Capacity-building

*PADMAJA KUMARI RANI, *DBALAKRISHNANAN, #TRPADHI AND *SUBHADRA JALALI

*Srimati Kanuri Santhamma Centre for Vitreoretinal Diseases, Jasti V. Ramanamma Childrens' Eye Care Centre, Kallam Anji Reddy Campus, LV Prasad Eye Institute, Hyderabad and #Retina vitreous services, LV Prasad Eye Institute, Bhubaneswar, Orissa.

Correspondence to: Dr Subhadra Jalali, Srimati Kannuri Santhamma Centre for Vitreoretinal Diseases, Kallam Anji Reddy Campus, LV Prasad Eye Institute, LV Prasad Marg, Hyderabad 500 034, India. subhadra@lvpei.org.

Tertiary Centres of Excellence in India have been at the forefront of the efforts against Retinopathy of Prematurity (ROP) - associated blindness. The epidemic of blindness from ROP; however, has now spread rapidly into large parts of interiors of developing countries due to improved newborn care facilities. Due to their knowledge and experience of more than a decade, these centres of excellence, both from child care and Ophthalmology care, now need to come forward in substantial measures and need to be supported by funds and programs so that concerns of neonatal eye-health, training, screening, prevention and treatment can get integrated and embedded into newborn critical care and health programs. This will protect newborn preterm survivors from losing the potentially good vision that they are born with, reduce the rapidly rising blindness epidemic, and also protect staff from potential high-value litigations.

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Retinopathy of Prematurity (ROP) has now emerged as a major problem in India and many other developing countries that are rapidly expanding the advanced neonatal care centres and assisted fertilization services. Both these set the stage for large numbers of babies at risk of ROP [1]. In many countries, it is not permitted to set up a neonatal centre without an ROP-screening. However, no such mandatory ROP-screening programs are being implemented in many developing countries when new centres are set up even with international expertise. For example, more than 700 Government sponsored Special care Newborn units (SCNU) have been set up across India, many with help from UNICEF, and almost none of these were mandated to have ROP-screening. Reasons seem to be either the lack of resources, planning or possibly a perceived difficulty in implementing too many things at one point. Now that these centres are established and doing life-saving work, there is an urgent need to fill the gaps quickly so that the survivors are not denied their 'Right to Sight' and can be prevented from becoming irreversibly blind. Tertiary-care Centres of Excellence (COE) now have a major role to play to achieve this effectively and expeditiously. This perspective is based on published journal articles, and personal interactions of the senior author (SJ) over last 15 years with various stakeholders of ROP-blindness prevention in India, with inputs from various COE across India.

EXPERIENCE AND CURRENT SCENARIO

The Ophthalmology, Neonatal and Pediatric Tertiary COE

teams in India have taken the lead since the 1990s to enhance the coordination and capacity-building for ROP-screening starting from their own hospital teams [2-5]. Various models have emerged over the last few decades across India that provide useful lessons and a foundation to now upscale the whole program. One needs to identify important gaps and effectively find solutions to bridge these gaps using known and innovative solutions.

Brief overview of currently running ROP models that have emerged:

- a. *Postgraduate students' training:* Coordinated programs between in-house Neonatology/Pediatrics and Ophthalmology departments. The All India Institute of Medical Sciences (AIIMS) - Rajendra Prasad Center, New Delhi; Post-graduate Institute of Medical Education and Research (PGIMER), Chandigarh; and few other centers have adopted this model. Postgraduates are exposed to defined ROP prevention and care protocols and variable hands-on training. The Ophthalmologists are mandated to visit the babies on a fixed date and time to provide screening and appropriate treatment.
- b. *Retina and Neonatology fellows, ROP-training:* Retina and neonatology fellows accompany the Consultants to learn ROP management including visits to the neonatology centres. Varying levels of laser hands-on training is provided. Aravind eye care systems and Sankara Nethralaya in Tamil Nadu are at the forefront of these models.

- c. *Digital camera-based training* to Non-Ophthalmologists and Ophthalmologists and child health providers so that a telemedicine model is used to enhance capacity of screening [6]. This model is being run by Narayana Nethralaya, Bangalore, and in some parts of Gujarat. In-house fellows are also trained in ROP-screening and lasers.
- d. *Dedicated ROP hands-on fellowship*: The LV Prasad Eye Institute, Hyderabad model is to provide training to various national and international eye specialists who have basic indirect Ophthalmoscopy/laser skills, in ROP-screening and lasers over one month. Teaching is by a team of neonatologists and retina specialists. Trainees learn how to reduce ROP incidence, take care of low vision and blind children with ROP, set-up programs in new areas, improve awareness, and interact with parents and colleagues. The program started in the year 2000 and trained more than 300 eye specialists globally.
- All the above four programs resulted in skilled manpower, many of whom have now set-up ROP-programs in their cities and countries. Mentoring and support for difficult cases continues beyond the training.
- e. *Intensive hands-on workshops*: AIIMS was the first group to initiate ROP workshops across India, under WHO-Ministry of Health program [1]. They for the first time brought together the Pediatricians/neonatologists and Ophthalmologists to a common platform. Though these were of a very short duration in different cities, they pioneered many more such regularly held workshops.
- f. *Setting-up of additional ROP-training and treatment hubs*: This has been carried out in partnership with various NGO such as Sight savers International, Orbis International, Miriam Hyman Memorial Trust, and Queen Elizabeth Diamond Jubilee trust. Many COE have helped other centres across India and neighbouring countries to enhance capacity and become training and treatment centres. Equipment and training costs are provided by the NGO while COE faculty provide their time, teaching materials and expertise. They also provide hand-holding and expert support as the program rolls out in a new centre. Such partnerships have provided expansion of ROP-related capacity.
- g. *Educational activities on ROP at academic meetings*: COE faculty from these subspecialties regularly conduct educational programs at local, state, national and international academic meetings. These are now attracting more and more delegates, indicating the felt-need for knowledge on ROP.

LACUNAE AND ROLE OF CENTRES OF EXCELLENCE

There are numerous lacunae (**Box I**) in our capacity for universal ROP-screening in preterm babies who are eligible for ROP-screening as per the National Neonatology Forum guidelines [7].

- * *Manpower*: Worldwide, there are huge gaps in manpower in neonatal and ROP care. In a telephonic survey in USA, Kemper, *et al.* [8] found that only 30% of Ophthalmologists cared for children less than one year of age, 11% screened for ROP, and only 6% treated ROP. Due to increased survival of preterms, many more personnel are required to tackle ROP at the bedside. The COE will need to train such professionals.
- * *Materials*: Few materials that are needed but not available in India are listed in **Box I**. Experienced faculty need to evaluate and validate upcoming low-cost, hand-held digital funduscopy devices and help procure equipments, through various Government and non-Government schemes.
- * *Educational material*: ROP is still not a very visible component of our routine curriculum. Members of COE who are on the curriculum committees have a huge role to play to make this vital but difficult change (changes in curriculum are challenging and time-consuming activities). Since it will take time to have this incorporated in the curriculum, meanwhile the faculty have to prepare e-learning modules [2] and other educational materials that are India-specific. This resource-building needs time, commitment and funds, and is a major activity that will make a difference.
- * *Infrastructure*: Up-gradation of quality care and screening and treatment facilities needs planning and funding (**Box I**). An early but welcome step in this direction is the recent program by the Ministry of Health, Government of India in its Rashtriya Bal Swasthaya Karyakram (RBSK). Under this program, congenital cataract, ROP and visual rehabilitation have been included. Monetary reimbursement for ROP laser treatment, under public-private partnership, has also been included as budgetary support. Monetary support for case detection has been allocated under the National Program for Control of Blindness (NPCB).
- * *Program strategy*: COE need to conduct operational research so as to translate the information from journals and textbooks to the bed side of babies [1-5]. This requires tertiary-care faculty to interact with local stakeholders and help to modify the service-

BOX I LACUNAE AND NEEDS IN CAPACITY BUILDING OF UNIVERSAL PRETERM ROP SCREENING

Adequate, Trained and motivated Manpower

- Neonatologists
- Neonatal nurses
- Ophthalmologists/technicians to screen
- Retina Specialists to treat and train in lasers
- Low vision and rehab specialists
- Optometerists to follow up for vision and refraction

Materials

- Dilute safe dilating drops like 2.5% phenylephrine
- Good Quality neonatal metal speculums and depressors
- Good quality portable Indirect ophthalmoscopes for each team
- Portable laser machine at a hub which can cover surrounding child care facilities.
- Less expensive and portable good quality neonatal digital fundus cameras (being developed)

Infrastructure needs to deliver quality neonatal care

- Adequate pulse oximeters, blenders and CPAP equipment
- Well prepared ambulances in case a baby needs to be transferred for treatment/screening to another hub

Educational and Information material

- National Guidelines for Prevention endorsed and distributed by Paediatric, Neonatal and obstetric societies
- National guidelines for ROP screening and treatment endorsed and distributed by paediatric, neonatal, and Ophthalmology societies
- Posters/ brochures for parents and family
- Neonatal nursing educational material
- Training material for concerned postgraduates and other doctors
- Regular CME, webinars, workshops, slide-scripts
- Advocacy material for govt. and non-govt. funding agencies
- Work towards ROP- inclusive curriculum update at all levels of medical education of various cadres of health care personnel.

delivery, and strategy that is best suited to the highly varied geographical, cultural, transportation and healthcare facility available in the area.

- * *Advocacy:* Tertiary-care faculty have very good public image, have a good support base of patients, students and staff, and have some accessibility to

BOX II ADVOCACY STRATEGIES FOR ROP

- Writing articles in popular print media.
- Participating in TV health shows and radio talks
- Conducting walks and runs on specific health days (example World prematurity day and Newborn Week in November or World Sight day in October).
- Using social media, flash mob and road shows
- Roping in local and national celebrities as brand ambassadors
- Talking to local leaderships at panchayat/ Zilla parishad etc and involving them in support
- Roping in child care industry and pharmaceuticals to distribute and advocate ROP screening educational materials.

funding agencies and to media; this provides them a unique opportunity to advocate ROP amongst various stakeholders (**Box II**). Improved awareness is the first crucial step in preventing ROP-blindness and increasing the demand from health service providers and managers as well as parents will provide an impetus to improve the quality and coverage of services for ROP.

An Indian study showed that only 65% of pediatricians knew about ROP and only 45% among these were aware about the time of screening [9]. A telephonic survey conducted among pediatricians in India reported a poor referral rate for ROP-screening with 34% of them not referring any babies [10].

CONCLUSION

The experienced leadership of ROP tertiary COE provides unique opportunities. A substantial task is to push for inclusion of neonatal eye screening and ROP-screening into curricula of various cadres of staff. They also need to work to provide hands-on training and course content, besides continuing operational research which can lead to ROP programs that are more effective, safe, sustainable and scalable. The goal of this integrated capacity-building, education, training and awareness-creation program is that in a couple of years the importance of preventive eye screening should become as well known to all as is the vaccination needs in a newborn baby. Today parents ask the doctor or the nurse, 'when are we going to start vaccination?' Tomorrow they should ask 'When is my preterm baby going to have first eye check-up' and they should promptly get the reply 'between 20-30 days of birth for sure! *'Tees din Roshni Ke'* (Thirty days to light) is our lead slogan for this mission.

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