



The Indian retinopathy of prematurity society: a baby step towards tackling the retinopathy of prematurity epidemic in India

Anand Vinekar¹, Rajvardhan Azad^{2,3}, Mangat Ram Dogra⁴, Venkatapathy Narendran⁵, Subhadra Jalali⁶, Pramod Bende⁷

¹Department of Pediatric Retina, Narayana Nethralaya Eye Institute, Bangalore, India; ²ROP Services, Bharti Eye Hospital, New Delhi, India; ³Raj Retina Eye Care Hospital, Patna, India; ⁴Department of Ophthalmology, Advanced Eye Centre, Postgraduate Institute of Medical Education and Research, Chandigarh, India; ⁵Aravind Eye Hospital, Coimbatore, India; ⁶LV Prasad Eye Institute, Hyderabad, India; ⁷Sankara Nethralaya, Chennai, India

Contributions: (I) Concept and design: A Vinekar, R Azad; (II) Administrative support: All authors; (III) Provision of study materials or patients: All authors; (IV) Collection and assembly of data: A Vinekar; (V) Data analysis and interpretation: A Vinekar, R Azad; (VI): Manuscript writing: All authors; (VII): Final approval of manuscript: All authors.

Correspondence to: Anand Vinekar, MD, FRCS, PhD. Professor & Head, Department of Pediatric Retina, Narayana Nethralaya Eye Institute, Bangalore, India. Email: anandvinekar@yahoo.com.

Background: India leads all nations in the number of preterms born annually. With over 3.5 million infants, a reducing infant mortality rate and an expanding base of rural neonatal intensive care units, the number of infants requiring retinopathy of prematurity (ROP) screening has dramatically increased. The number of ROP specialists in the country is currently inadequate. Leading ROP specialists of the country initiated the Indian ROP (IROP) society to address these challenges.

Methods: In 2016, the IROP society was conceived and registered as a professional body with a mission to prevent needless blindness from ROP by promoting standards of excellence. A national online membership drive was carried out. The data collected in this survey was analyzed to collate information on past training, practice patterns, ease of screening and treatment, use of wide-field imaging and willingness to be certified.

Results: Of the 113 members at the time of submission, 67.3% were male. 88.5% were formally trained for ROP and 85.8% were vitreo-retinal specialists. Of the practicing members, 96% were “comfortable” with screening and 86% with ROP treatment and this correlated with training ($P=0.001$ and $P=0.002$ respectively). Only 25.7% performed vitreous surgery for ROP. Wide field imaging was used by 33% of members in their practice and 52% of those who did not, wanted to use it in the future. Members who used imaging performed more number of laser treatments than those who did not ($P=0.008$). Laser was the preferred modality of treatment for 98% of members. A majority of the members (92.5%) were willing to be audited.

Conclusions: The IROP society is a novel platform for ROP specialists to collaborate. The society has setup short, mid and long-term goals to make ROP care more accessible and affordable with appropriate use of technology.

Keywords: Retinopathy of prematurity (ROP); India; screening; society; wide field imaging

Received: 27 March 2017; Accepted: 14 April 2017; Published: 05 June 2017.

doi: 10.21037/aes.2017.04.02

View this article at: <http://dx.doi.org/10.21037/aes.2017.04.02>

Introduction

India leads all countries in the number of preterm infants born annually (1). With over 3.5 million added each year, coupled with improving neonatal standards of care across the public and private health care delivery system alike, survival of these tiny infants has increased dramatically over the past two decades (2). Overall, infant mortality has shown a downward trend in most states. These factors contribute to an increase in the “at risk” population for retinopathy of prematurity (ROP). A vast majority of these preterm births still occur in rural India where the awareness about ROP is still lacking and specialists are scarce, thereby adding to the burden of preventable ROP blindness (3,4).

With less than 100 estimated ROP specialists across the nation and fewer than 20 centers that are equipped to manage all aspects of ROP care, there is an urgent need to scale up this scarce expertise. Furthermore, with a recent Supreme Court of India judgement in 2015 on ROP (5) and few other cases of medico legal negligence related to ROP care since then, the spotlight is focused on providing appropriate, accessible and affordable ROP care using a systematic and documented process that will pass legal scrutiny and provide the highest standard of care to urban and rural babies alike.

The Indian Retinopathy of Prematurity (IROP) Society was initiated in July 2016 by some of the leading experts in the field to bring together ROP specialists from across India to share best case practices, promote uniform guidelines, enhance screening efforts into unreached areas through training and technology, give impetus to research and development, innovate newer tools and processes and create a medico-legal framework to foster ethical and clinical excellence in ROP management.

This manuscript summarizes the society’s objectives, the demographic and bio-profiles of its initial members and outlines the short-term, mid-term and long-term goals of the society.

Methods

Initiation of the society

The IROP society was conceived by the authors (R Azad and A Vinekar) and other charter members (MR Dogra, V Narendran, S Jalali and P Bende) who organized a 2-day workshop in July 2016, in Bangalore, India. Thirty ROP specialists who represented different states or regions of the country were also invited as participants. During this

workshop, each representative summarized their regional ROP data and experience highlighting their current challenges and limitations. These were summarized and presented to the National Task Force of ROP, Government of India, New Delhi in August 2016. The vision, mission and objectives of the IROP society are summarized in *Table 1*.

Online membership and data collection

Subsequent to the first workshop, an online membership drive was initiated by creating a Google Form. This link was shared on WhatsApp groups of major societies including the Vitreo-Retinal Society of India (VRSI) and other state and city chapters and societies of ophthalmologists. Those involved in ROP care (screening and/or treatment) were invited to fill the online form. Approved members were included in the IROP Society’s WhatsApp group and subsequent society activities were shared and monitored through this medium.

During the online enrolment, attempts were made to collate information on the screening and treatment numbers, strategies and outcomes of these members. An emphasis on past training, research, ease of screening and treatment, use of wide-field imaging and willingness to expand into the outreach was also assessed. The key questions and parameters that were assessed in the online form are summarized in *Table 2*.

The online data collected prior to and until the preparation of this manuscript was collated and analyzed to summarize the demographic details, bio profiles, and screening and treatment strategies of the members using the JMP Statistical software v12 (SAS, Car, NC).

Results

The online form was filled by 113 members, 76 (67.3%) male and 37 (32.7%) female, from all states and regions of India. Of the 81 members who provided details about their fellowship training, 70 members (85.8%) were fellowship trained in vitreo-retina, 6 members (7.4%) in pediatric ophthalmology, 1 member (1.6%) in pediatric retina, 1 (1.6%) in cornea and the remaining 3 members (3.6%) were not fellowship trained.

Of the 113 members, 101 (88.5%) had undergone formal ROP training. The training was for screening only or treatment as well. The duration of the training was variable since the institutes from where it was obtained differed and because ROP training was often provided during or

Table 1 The Indian retinopathy of prematurity society: vision, mission and objectives

Vision
Bridging barriers and breaking boundaries for retinopathy of prematurity (ROP) care
Mission
To prevent blindness in babies with ROP by promoting standards of excellence
Objectives of the society
Pan-India collaboration of specialists involved in the care of ROP
Highlight best case practices in ROP screening and treatment
Circulate and adhere to uniform guidelines that are in concurrence with the Indian national guidelines
Promote the highest ethical standards for ROP treatment
Encourage technological advances that improve the care of babies undergoing screening or treatment
Provide impetus to innovation that will enhance access and acceptance with ROP care givers and their beneficiaries
Develop and implement low cost technological advances that improve ROP management
Collaborate in multi-center trials which advance the field of ROP
Liaison between ROP caregivers and the Government to integrate ROP care with the national goals
Safeguard the medico-legal interest of ROP caregivers and their beneficiaries

Table 2 Key aspects and questions in the online membership form and survey

Demographic details
Name, age, gender, work address, type of practice, contact details, professional memberships
Qualifications
Residency, fellowship, sub-specialty and years in practice
ROP training
Duration, location, type
ROP practice
Number of centers, number of babies screened and treated, comfort with screening, treatment, surgery, anti-VEGF, research and publications in ROP, attitude towards ROP, willingness to upgrade/train others
Wide-field imaging
Availability, integration into practice

ROP, retinopathy of prematurity; anti-VEGF, anti-vascular endothelial growth factors.

throughout the course of the entire fellowship rather than as a single one-time or dedicated course in most cases. The mean duration was 9.3 months (range, 0–96 months).

Of the members, 108 (96%) were “comfortable” with ROP screening and this was significantly associated with having been formally trained ($P=0.001$). Of the members, 97 (86%) were “comfortable” with performing laser and this was also significantly associated with being formally trained

($P=0.002$). Of the 113 members, 29 (25.7%) performed vitreous surgery for advanced ROP, however this did not correlate with the ROP training ($P=0.02$) or the duration of ROP training ($P=0.16$).

To correlate the effect of training on the number of babies screened and treated, we used a density ellipse to fit the data set after excluding one outlier member who skewed the data set because of a program that screened

for ROP in several centers across his region (4). On analysis of the remaining members, duration of training correlated positively with an increase in number of babies treated ($P < 0.0001$) and not with number of babies screened ($P > 0.05$).

To determine an appropriate duration of training, we fit a density ellipse to correlate this with the outcome variables of screening and treatments. The mean duration was 8.6 months using this fit. We used the cut-off of 12 months to determine its influence on the outcome variables. We found that those who trained for more than 12 months performed significantly more number of lasers than those who trained for less than 12 months ($P < 0.001$).

With the recent popularity of the use of anti-vascular endothelial growth factors (anti-VEGF) agents in ROP, we analyzed member preference for its use as a mode of therapy. Of the 113 members, 41% had never used anti-VEGF for ROP, and 2% of respondents claimed that it was their first choice of therapy. The remaining 57% used it selectively and maintained that laser was still their first choice of therapy.

We analyzed the attitude, access and availability of wide-field imaging in screening and documenting treatment. Of the 81 members who provided this information, 54 (67%) did not have access to a RetCam (Clarity MSI, USA) or an indigenous wide-field ROP camera (Neo, Forus Health, India) and the remaining 27 members (33%) used one or both of these devices in their routine ROP practice. Of those who did not have either device, 43 members (52.8%) were interested in incorporating imaging as part of their current practice. Correlating the use of wide-field imaging with output of screening and treatment, those who used imaging routinely screened more babies in more centers although this was not statistically significant and performed significantly more treatments each month compared to those who did not ($P = 0.008$). Of the 81 members, only 15 (18.5%) had one or more peer review publications in ROP.

As part of the membership obligation, the members were asked if they would allow a team from the IROP society to visit their center(s) and audit their data and validate their screening and treatment protocols and outcomes. Six of 81 (7.4%) members denied permission to be validated. Four of these six members were not trained for ROP and had very low numbers of babies screened and treated annually.

Discussion

The Indian ROP society was setup to serve as a platform

for the country's ROP specialists to collaborate with each other and contribute as a cohesive entity with other groups of physicians, predominantly neonatologists, pediatricians, obstetricians, nurses to promote best case practices (6,7,8), improve the current situation and train "new ROP" specialists to fill in the current lack throughout the nation. The society currently has not opened membership to non-ophthalmologists, but has plans to include other groups of physicians as associate members.

Despite an aggressive online membership drive across the country, the current membership is a mere 113 specialists, of which less than 100 are comfortable with screening and treatment. This reiterates the current lack of specialists. There are some states or regions of the country where there are only 1–2 ROP trained ophthalmologists, placing these regions at a high risk for ROP blindness. In some regions, ROP specialists only perform screening and refer the babies to other specialists (often in another state) for treatment. With the recent increase in the number of special newborn care units (SNCUs) in the Government sector, most of these 637 units do not have any ROP specialists. It is imperative to link them to the current IROP members in their respective regions until new specialists are trained and certified for these centers. There is an urgent need to train more ophthalmologists for ROP management and only a concerted and focused strategy would be able to address this challenge in a short time.

The results of the online survey filled by the members during the enrollment highlight key aspects of the current situation. Firstly, over 85% of ROP specialists are retina specialists with the rest either pediatric ophthalmologists or general ophthalmologists who were ROP trained. Despite over 800 registered VRSI members, less than 100 of these are involved in ROP care. This needs to be further investigated. Secondly, formal training for ROP is fortunately widespread among the members with over 89% having been trained for screening or treatment. As expected, training correlated with comfort with screening and laser treatment but interestingly correlated with increase in the number of babies treated annually. Furthermore, trained members were more confident about performing more treatments if they had more than 12 months of experience and were more amenable to being audited and certified by the IROP society. Thirdly, the survey highlights the increasing popularity of wide-field imaging in routine ROP practice. One out of every 5 members (21%) had access to imaging and more than 50% of those who did not, wanted to incorporate this technology. The recent supreme court

Table 3 A summary of goals of the Indian ROP society—short, mid and long-term goals

Short term goals
Enhance nationwide membership, collaborate with the pediatric societies, create a website, ratify a common ROP guideline, promote regional and state-wide chapters
Intermediate goals
Audit and accredit all members, create a directory of certified “screeners” and “treatment providers”, train the trainers, standardize the training curriculum, promote research and multi-center studies
Long term goals
Collaborate with the Government, enhance advocacy, influence policy, mentor other organizations and regions

ROP, retinopathy of prematurity.

judgement on ROP negligence (5), imaging supported reimbursement for laser treatment promised by the Government and the importance of photo documentation in assessing treatment outcomes are some of the reasons for this increasing popularity (4,6). Furthermore, as previously reported from India, imaging improves follow-up even in rural babies when the family is shown the retinal images of their baby (9). The survey results support this observation since those who integrated imaging in their practice performed more treatments than those who did not. Finally, laser treatment appears to be the first choice for most specialists. The current national guidelines promote laser as the “gold standard” restricting the use of anti VEGF agents to select cases and as rescue therapy (10).

The future roadmap of the society could be divided into short-, mid- and long-term goals and are summarized in *Table 3*. With no similar ROP societies as a yardstick, the Indian ROP society must charter its own path and learn from its own mistakes. The current challenge would be verifying and assessing the veracity of the current members before an accredited database is shared with the Government of India, the National Neonatology Foundation and the Indian Association of Pediatrics. If there must be a paradigm shift in the way we practice ROP in India, with the vision of making it accessible, affordable and achievable, the IROP society must move forward, even if it is one baby step at a time.

Acknowledgements

The authors want to acknowledge the members of the Indian Retinopathy of Prematurity Society for their active contribution in the online survey and Dr. Shwetha Mangalesh for the statistical analysis.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The study did not involve patient care or information. The Institute Research Board (IRB) of Narayana Nethralaya Eye Institute, Bangalore, approved the study.

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doi: 10.21037/aes.2017.04.02

Cite this article as: Vinekar A, Azad R, Dogra MR, Narendran V, Jalali S, Bende P. The Indian retinopathy of prematurity society: a baby step towards tackling the retinopathy of prematurity epidemic in India. *Ann Eye Sci* 2017;2:27.