

## Establishing support groups to support parents of preterm babies with retinopathy of prematurity: A pilot study

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India has the highest number of preterm births in the world, which along with low birth weight, are significant risk factors for retinopathy of prematurity (ROP). One of the challenges in combating visual loss from ROP is the lack of information and awareness among parents of preterm babies. The objective of establishing ROP parent support groups was to support parents of children with ROP by counseling, information and resource sharing, and general guidance. As part of a major initiative to combat ROP across four states in India, a strategy to develop parent support groups was developed and a pilot project was implemented in three cities. In collaboration with identified eye institutes, five ROP parent support group sessions were conducted in these cities. The concept is still in its initial stages of implementation and data are not yet available on the impact of the support groups. However, the overall turnout for the meetings was low as only 30% of parents invited attended meetings. Initial learning and experiences suggest that parent support groups could have a significant role to play in providing many benefits especially in improving awareness, knowledge, and compliance, alleviating anxiety, and empowering parents.

**Key words:** India, parent support groups, preterm infants, retinopathy of prematurity, uptake

In India, 3.5 million babies are born prematurely annually (2010 data),<sup>[1]</sup> the highest number in any country globally.<sup>[2]</sup> Preterm babies are at risk of visual impairment and blindness from retinopathy of prematurity (ROP), and in India, the population at risk are those born with a gestational age <34 weeks or with a birth weight of 2000 g or less.<sup>[3]</sup> Control of visual loss from ROP requires high-quality neonatal care, timely screening, and urgent treatment, if required, which are very effective at preventing visual loss. The active engagement of parents is critical. For example, by providing kangaroo care and breastfeeding both of which lead to better neonatal outcomes. After discharge, parents may need to bring their infant back for screening and treatment if indicated. Infants treated for ROP require frequent and long-term follow-up.

Parents of preterm infants in neonatal units often have difficulty in forming attachments with their newborn and can experience anxiety and depression.<sup>[4]</sup> In addition, ROP screening is an additional cause of anxiety. It is well recognized that anxiety and depression influence cognitive function and decision-making,<sup>[5]</sup> and that sharing experiences can help alleviate anxiety. Several studies have established the importance of social support in improving overall health outcomes in people with chronic health conditions,<sup>[6-8]</sup> but there

is scant evidence of the benefits of support for the parents of preterm infants.<sup>[9]</sup> The objective of establishing ROP parent support groups was to support parents of children with ROP by counseling, information and resource sharing, and general guidance.

### Methods

This initiative was embedded in a pilot ROP-screening program which was implemented in four states in India between 2014 and 2019. The Parent groups were set up in Only 3 cities viz Hyderabad, Bengaluru & Pune. The ROP screening initiative was running across 4 states but the parent support groups were set up in only 3 cities as a pilot towards the end of the screening programme. Participating institutions had to fulfill the following criteria: Providers of tertiary eye care services with more than 5 years' experience of ROP management (screening, treatment, and rehabilitation), with appropriate human resources, such as counselors experienced in counseling parents of children with ROP, and adequate infrastructure.

A strategy with protocols was developed to ensure organizational and community readiness, with guidance on effective implementation, a template for evaluation, and establishing a process to ensure sustainability.

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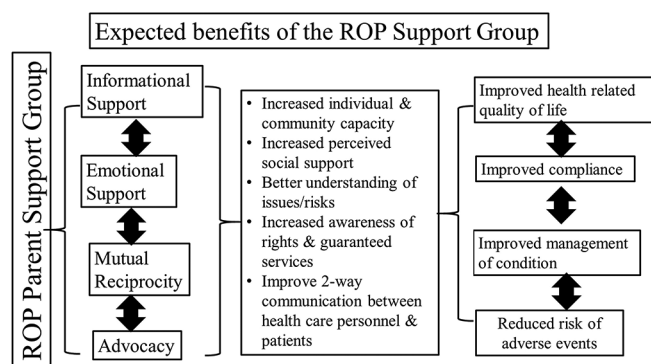
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**Table 1: Parent support group meetings held across the identified eye institutes**

City	Approximate duration of session(s)	Number of families invited	Number of families attended	Who attended the meeting
Hyderabad	120 min	30	10	Most were parents and in some cases only the mother with a grandparent or other relatives. Infants had different stages of treatment for ROP.
	90 min	40	15	
	90 min	40	08	
Pune	120 min	80	13	All the participants were parents of preterm babies referred for ROP in the unit.
Bangalore	90-120 min	60	30	All parents of babies at risk of eye problems were included in a single parent group. Participants were introduced to many eye conditions which could affect babies including ROP.

ROP: Retinopathy of prematurity



**Figure 1: Expected benefits from the retinopathy of prematurity (ROP) parent support group. ROP: Retinopathy of prematurity**

Parents/caregivers of preterm babies attending the facilities for ROP screening or treatment were invited to take part in support groups after explaining the potential benefits. In Bangalore, parents of babies at risk for all eye conditions including ROP were invited. The local organizing team collected contact information to coordinate, set up meetings, and to obtain consent. The support groups took place on the same day as ROP screening/treatment for logistical reasons. The first meeting was facilitated by health professionals or counselors but thereafter meetings were to be facilitated by a member (parents/caregivers) of the group. The agenda for the first meeting was drawn up by the health professionals; however, the topics of the discussion during subsequent meetings for each group were discussed and selected by the participants.

## Results

Between December 2018 and May 2019, five parent meetings were held in Hyderabad (3 meetings), Bangalore (1), and Pune (1) [Table 1]. Only 30% of the 250 parents invited participated. Although it is too early to assess the impact of these groups, some early experiences are reported.

### Parents' perspectives

Most parents wanted to understand the long-term risk of blindness from ROP whereas others requested information on other complications of preterm birth. Parents expressed the challenges they face in bringing their baby for screening and treatment and others were concerned about how to take care of a preterm baby and a child with poor vision. Parents/caregivers were not completely sure how useful these groups

would be and whether they would be able to attend regularly given the logistical challenges they face. Parents did not want the sessions to take place more than once in 2–3 months and requested that meetings coincide with clinical follow-up.

### Providers' perspectives

Efforts were made to ensure that a doctor and counselor were available in every session to answer questions, at least for initial meetings. Once the parent facilitator was well trained, they could take on the role of basic counseling or invite the health care staff when required to answer parents' concerns.

One provider indicated that meetings should not be too long as babies became restless.

Responding to the logistical challenges of face-to-face meetings and the need expressed by parents for ongoing information, support, and learning from others' experiences, in Hyderabad efforts were made to create a WhatsApp group, which included clinicians and a psychologist. Parents were encouraged to post their concerns and queries, which could be answered by other parents or professionals. The WhatsApp group was also used as a platform to communicate important information to parents.

## Discussion

Based on these initial experiences, further meetings will take place quarterly, they should last a maximum of 2 h, and efforts are required to ensure clinical examinations take place on the same day. A parent group facilitator guide has been developed to facilitate the smooth functioning of the groups and encourage scaling up efforts. Given the initial success of the WhatsApp group, establishing a dedicated helpline for parents is being explored.

The low turnout of the parents for these meetings is indicative of the challenges that this kind of initiative has. It is imperative to have a focused or specific approach to inviting parents. It is very crucial to earn the trust of the parents for them to be more accepting and find the initiative beneficial for a mutual support system to improve overall care of their babies. The initiative has to drive home the message to the parents that ROP is a lifelong condition and regular follow-up until adolescence or beyond is required.<sup>[10-12]</sup>

## Conclusion

Parent support groups for ROP have the potential to afford many benefits [Fig. 1], and further operational research in

larger groups over an extended period of time is required to help take this initiative further.

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### Conflicts of interest

There are no conflicts of interest.

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