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PROPERA(Pakistan ROP Research and Educational Alliance): **Aims And Accomplishments Over 3 Years** Mian UK, Noorani S, Cheema A, Mukhtar MA, Moin M *Writing group for PROPERA*

Background

Pakistan currently ranks fourth in number of premature births (>15%) and the IMR of Pakistan in 2015 was 65.8. As mentioned by Dr. Gilbert, Pakistan is going to experience the ‘third epidemic’ of ROP as countries with IMR below 60 have a high risk of prematures surviving with deficient support systems for preventing and treating ROP. Thus, Pakistan faces a large premature infant population that can go blind. Convincing ophthalmologists and neonatologists to screen and treat for ROP is challenging. They are over worked, under staffed and focused on trying to keep a premature alive. They can establish ROP screening programs if they are approached correctly and are provided with essential materials and training. In 2012, we were aware of only two private hospitals that were doing routine screening for ROP. The Pakistan Retinopathy of Prematurity Education and Research Alliance (PROPERA) was created in 2013, we present the outcomes of our 3 year experience.

Aims

- To save premature infants from blindness due to ROP
- To create awareness of ROP within Pakistan
- To create initial screening criteria and oxygen protocols criteria
- To gather data on disease burden
- To establish the PROPERA network in NICUs all over the country

Methods

- Initial contact was made by invited lectures on ROP, followed by frequent and multiple contacts.
- Review articles written and published in local Journals.
- Lectures and symposia arranged at all major national ophthalmology and pediatric meetings.
- Key interested people and institutions identified.
- Collaborative discussions for preliminary screening and oxygen protocols.
- Establishment of centers for screening and collection of data.
- Creation of capacity by training workshops.
- Creation of funding support and collaboration.

Accomplishments

- Awareness.** More than 20 lectures at institutions, 7 invited lectures at national meetings, 5 Symposia at national meetings and 2 review articles in national journals
- Consensus initial screening protocols.** Gestational age of 35 weeks or less and birth weight of 2 kg or less. Oxygen protocols with SiO₂ between 91-94%
- Organized pilot screening programs** at 5 hospitals in 4 cities. Data on screening of approx. 1,500 patients and 40 patients treated for Type 1 ROP collected. Confirming the relevance of the initial ROP protocols.
- A **core group** of 15 ophthalmologists and neonatologists have become committed, with another 18 showing strong involvement. Six key institutions in 4 cities have become committed with 12 other institutions in a total of 10 cities have started screening or shown strong interest.
- Create capacity of trained screeners;** an educational workshop was created and has been run 3 times with training of nearly 70 people.
- Support** from professionals (Drs G Quinn, C Gilbert) and institutions (Adamjee Eye Hospital \$12000, Qarshi \$125,000, Child life foundation inc, Aga Khan University)
- Educational material** developed to educate parents with different levels of education and languages. (written material, Cartoon story and animation)
- Development** of standard 90 min training programs; ROP education, hands on training for examination and how to start a ROP screening program



Conclusions

The critical aim in involving any institution is to identify the key ophthalmologist and neonatologist and convince them of the potential risk of blindness due to ROP and its clinical and medico-legal consequences. ROP coordinator has been found to be an essential requirement for such programs. Five institutions across the country have joined PROPERA and have established ROP screening programs, despite all obstacles.

Next Steps

- Creation of PROPERA website for information and resource for all aspects of ROP
- Distribution of Database software for uniform data collection
- Creation of an Outreach team for support of new sites.
- Funding for equipment and personnel.
- Establish a Mobile Retcam Facility.

PROPERA Network

- **Karachi**
National Institute of Child Health / Jinnah Post graduate Medical Center
Aga Khan University (support)
Adamjee Eye Hospital (support)
- **Lahore**
Lahore General Hospital
Hameed Latif Hospital (support)
Punjab Children's Hospital
Fatima Memorial Hospital
Ganga Ram Medical Center
- **Islamabad and Rawalpindi**
Al Shifa Trust eye hospital / Pakistan Institute of Medical Sciences
Armed Forces Institute of Ophthalmology
Shifa International Hospital
- **Peshawar**
Lady Reading Hospital

RED established **BLUE preliminary**