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A Telemedicine Success Story For a Population in Dire Need

With a dearth of ROP specialists, India has improved outcomes using an outreach network of remote screening sites.

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Retinopathy of prematurity remains one of the most challenging—and most devastating—retinal conditions, as lifelong blindness hangs in the balance. Even western societies struggle to meet the need, but in the developing world the problem is magnified by many structural problems inherent in the healthcare system's present capabilities. Successful management requires highly skilled experts, wide access to screenings of premature infants and the ability to offer rapid medical intervention. All are in short supply.

A telemedicine initiative in India called KIDROP has garnered much interest since its inception in 2008. The Q&A below explains its origins, how the work is conducted and what has been achieved over the last three years.

Q. What is the extent of ROP among the Indian population, and what is being done to combat it?

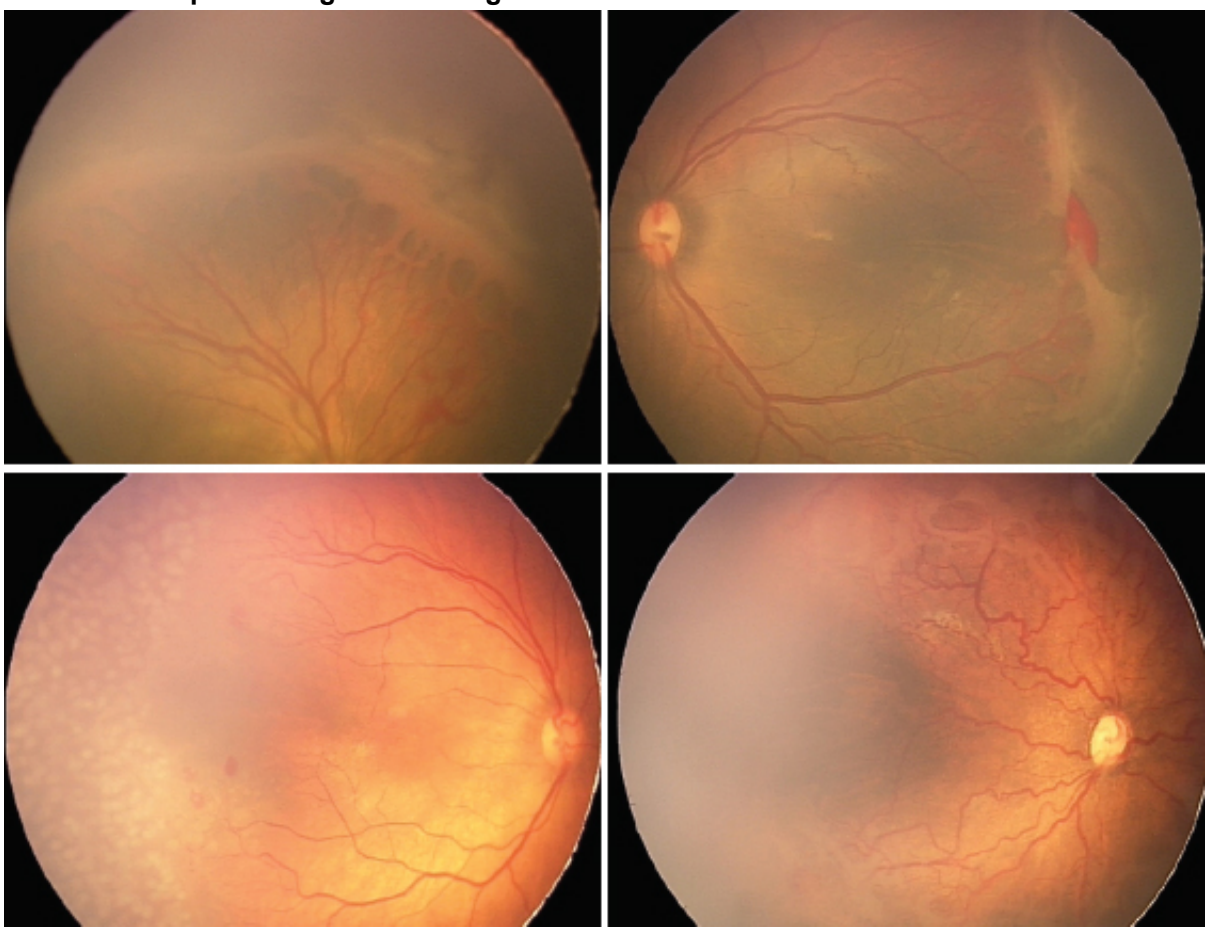
Childhood blindness is one of the priorities of VISION 2020: The Right to Sight, an ambitious initiative of the World Health Organization and the International Agency for the Prevention of Blindness. Begun in 1999, its goal is to prevent blindness in 100 million people by the year 2020 by supporting more effective interventions that can be integrated into existing healthcare systems.

In India, childhood blindness has not yet received the emphasis it deserves either from governmental or non-governmental agencies. Thus far, their efforts have concentrated on providing adult cataract services. Although that is certainly a noble and welcome initiative, the predicament of India's childhood blindness population can rightly be called an epidemic. One-fourth of the world's blind children live in India.

The most common causes of childhood blindness in India include overall globe abnormalities (24%), corneal disease (28%), pediatric retinal etiologies (22%) and pediatric cataract (11%). Whereas the incidence of vitamin A deficiency is on the decline, as are corneal causes of blindness, retinal causes have received very little attention. That is rather unfortunate when one recognizes that ROP is the most preventable retinal cause of blindness.

Mothers receiving education on the Tele-ROP process.

KIDROP staff performing a screening at a remote site.



ROP images taken with the RetCam Shuttle by KIDROP staff.

Of the 27 million annual live births in India recorded in 2007, over two million babies (8.4%) are said to have been born below 2,000 grams and considered to be at risk for ROP. Among the Indian population, the condition affects between 37% and 54% of infants born underweight. About 10% to 20% of those who develop this disease will require treatment within 48 hours of detection to prevent irreversible and permanent blindness. Studies have shown a higher incidence of severe ROP in India even among those infants considered to be at low or no risk (birth weight of 1,500 to 2,000 grams), further increasing patient volume.

Clearly, the need is enormous. Unfortunately, there are only about 400 retinal surgeons in India, and less than 20

are ROP experts. The incidence rates mentioned above work out to roughly 37,000 to 54,000 cases per year *per ROP expert*, of which 10,000 cases per expert might require urgent care—in a country of 3.2 million square km.

This skewed demand/supply ratio begs for an alternate method to reach needy infants, especially in rural areas.

Q. What is KIDROP, and how was it created?

KIDROP stands for “Karnataka Internet-Assisted Diagnosis of ROP.” It is based on the “Triple T” philosophy: **T**ele-ROP, **T**raining of peripheral ophthalmologists and ophthalmic assistants, and **T**alking to neonatologists, pediatricians and gynecologists.

In March 2008, Narayana Nethralaya Postgraduate Institute of Ophthalmology, in Bangalore, pioneered the nation's first Tele-ROP network that trained nonophthalmologists (technicians) to screen infants in rural areas of Southern Karnataka, where there are no specialists, within a radius of 300 km from Bangalore. Some parents have visited a KIDROP site from up to 100 km away, further extending the reach of the network.

The program has also developed a novel IT network needed to allow specialists in Bangalore to diagnose these infants remotely. The pilot project initiated in 2008 started with five centers. As of the first quarter of 2011, KIDROP has grown to screen in 25 centers spread across the southern six districts of Karnataka State in Southern India. Most of these are in rural or semiurban centers. None had ROP screening capabilities prior to inclusion in KIDROP.

Patients are required to pay just 30% of the normal cost of care, and even that is waived if the family cannot afford it; the remainder is subsidized by support from the Narayana Nethralaya Foundation and/or waived by caregivers and facilities. Also, in 2009 KIDROP entered into India's first public-private partnership in infant blindness prevention with the National Rural Health Mission, a program of the Ministry of Health and Family Welfare of the government of India.

Some revenue is generated from private hospitals that participate. Government hospitals are not charged any fee. No child has ever been denied treatment for lack of financial resources. The financial viability of this model is a topic of study at the Indian Institute of Management. The institute's work has demonstrated the economic benefit of KIDROP as the best strategy for ROP implementation in remote areas with predominantly poor patients.

Q. What technology is used?

Screening is conducted using the RetCam Shuttle from Clarity MSI, a portable widefield digital imaging device capable of imaging 130 degrees of the retina of neonates. A single Shuttle unit travels to all the neonatal centers within one zone. It is equally suited to use in both clinical and hospital settings. KIDROP's field workers are able to store, read, analyze, grade and upload these images from the rural center itself.

Narayana Nethralaya has noncommercial collaborations with i2i Telesolutions, a local IT company that has developed an ingenious Internet-based picture archiving communication system. This hardware-software platform uses a patented compression technology (ABO compression) that allows live uploading, viewing and reporting of images from any part of the globe directly accessed by the KIDROP doctors on their PCs and smart phones. Backup images reside on file servers at two separate locations.

Since December 2009, the images can also be viewed on the iPhone on a specially designed application. The reports created by the remote ROP expert on the iPhone are saved in PDF form and are uploaded to the server through the cellular network, reducing dependence on the variable Internet speeds.

In addition, a binocular indirect ophthalmoscope and a handheld SD-OCT device are available whenever needed.

Q. How is a screening session conducted?

Site visits take place weekly. A four-person team (technician, manager, driver and ophthalmologist) transports the necessary equipment to the neonatal intensive care unit (NICU) at a network site. All infants born prior to week 35 of gestation and/or below a weight of 2,000 grams receive a dilated fundus exam prior to discharge.

The examination, imaging session and even treatment are carried out at the bedside of the infants, most of whom continue to be housed in the incubator. The standard protocol calls for seven images to be captured per eye, although the technician may elect to obtain additional ones if called for. At the beginning of the program, technicians often obtained more images but as they gained expertise it was possible to limit the screening to conform to the standard Photo-ROP guidelines. Results are reviewed live by an ROP expert via laptop or mobile access to the images captured by the technician.

Given the great distances some parents must travel to reach the screening site (up to 100 km in some cases), diagnosis is required without delay, and that goes for treatment as well, if feasible. To allow this, the field technicians were trained to “read” the images using a unique algorithm, and their results were compared against the gold standard of indirect ophthalmoscopy by an onsite ROP expert.

Technicians assess the images and categorize the case in one of three ways:

(1) Urgent referral to an ophthalmologist needed (ie, inferring that the disease imaged requires treatment or needs very close follow-up).
(2) Infant needs follow-up (ie, has a stage of ROP that is not alarming and does not warrant treatment just yet).
(3) Infant can be discharged (ie, complete maturation of the retinal vessels has been confirmed up to the ora serrata in all four quadrants at two successive visits).

Whenever possible, same-day laser treatment is given at the rural center, using the ETROP guidelines.

Q. What are some of KIDROP's accomplishments?

In 36 months of activity that began in March 2008, using India's first portable RetCam Shuttle, KIDROP has screened over 3,500 unique infants in over 25 neonatal care centers spread over six districts of Karnataka covering a radius of over 350 km. Over 400 infants have received laser and other treatments in rural centers, without having to travel to the city. Over 200,000 images in over 17,000 imaging sessions have been stored in a database using an award-winning IT platform that allows the expert to read and diagnose the images live on his or her iPhone or iPad.

With 25 access sites brought online in less than three years, this network has been named the world's largest Tele-ROP network managed by a single center (the largest network in the US has 15 sites). Thus far, KIDROP has trained over 14 teams for immediate placement in outreach areas in the states of Karnataka and Maharashtra.

India Today, the nation's leading news magazine, has cited KIDROP's technology in its “Top Ten Medical Innovations of 2009” report and lauded its social contributions. *The Harvard Business Review* has cited KIDROP and its technology as an example of “reverse innovation” for the more developed world to emulate. Other public and professional media have praised different aspects of KIDROP. Even India's minister of external affairs has named it a “unique initiative to reach the rural underserved.”

KIDROP's research has led to a discovery of a new risk factor for ROP (thrombocytopenia, cited in *Retina*), a new method of imaging infants (handheld SD-OCT, published in *Eye*) and previously unreported macular changes in early ROP (just published in *IOVS*, May 2011), among several other ongoing projects.

Q. What is expected in the future?

KIDROP has initiated partnerships with other states in India and with the government of India to expand the reach of this initiative so that more infants in rural areas would benefit. Since 2010, the project has partnered with the Ministry of Health and Family Welfare to add another 36 centers, serving north Karnataka and central Karnataka,

which will be operational by 2012. KIDROP assures free training, reading and treatment for the infants screened under this initiative.

Other countries—including Thailand, Mexico, Indonesia, Qatar, Ghana and Kenya—are at various stages of collaboration with the KIDROP team to initiate and support a similar program in their respective countries.

Clearly, the extent of childhood blindness in India is sobering and deserves greater attention and efforts. The collaborative efforts demonstrated by KIDROP's success can hopefully be seen as a model for future efforts in India and other developing nations. **RP**

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