

Regional workshop on retinopathy of prematurity November 14-16th 2005 Lima, Peru

Report



Supported by:
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EXECUTIVE SUMMARY:

The workshop was held in Lima, Peru, and was attended by over 60 neonatologists and ophthalmologists from 18 countries in South and Central America and the Caribbean. The workshop provided an opportunity for those actively involved in programmes for the control of retinopathy of prematurity to meet, to share experiences, and to present their programmes. The purpose of the workshop was to promote actions that would lead to higher coverage of screening and treatment programmes, and to improve the quality of current programmes. The anticipated outputs were a) draft guidelines on all aspects of ROP screening and treatment for the region, to include neonatal and ophthalmologic components, and b) a list of priority actions for the next 3 months, and for the next 12 months.

The workshop was opened by the President of the Peruvian Ophthalmological Society, Dr Jorge Alvarez, and Dra Luz Gordillo welcomed participants and explained the purpose of the workshop. Over the course of the next 3 days, each country presented their programmes, and presentations were given on specific topics (Time table for workshop, Appendix 1). There were 4 sessions of group work, in which participants discussed how programmes could be improved both in terms of quality and coverage; to start the process of drafting regional guidelines; to discuss advocacy issues, and to outline curriculae for different levels of staff (neonatology and ophthalmology). At the end of the workshop a small working group was developed, who would work on the regional guidelines (see Appendix 2). A decision was made to arrange a follow up meeting at the International Congress of Ophthalmology, which will be held in Sao Paulo in February 2006.

SUMMARY OF PRESENTATIONS:

Activities of IAPB Childhood Blindness Committee. Dra Andrea Zin

The control of childhood blindness is one of the priorities of the International Agency for the Prevention of Blindness-LA (IAPB-LA). The Childhood Blindness subcommittee recognizes the wide regional variation in the major causes of blindness in children, however ROP has been reported to be responsible for up to 38% of severe visual impairment/blindness in Latin America. The main aim of this subcommittee is to stimulate and support actions that promote the establishment of national plans with the participation of Ministries of Health and the implementation and/or increase of coverage of ROP screening and treatment programmes.

VISION2020, and ROP as a cause of blindness in children. Dra Clare Gilbert

VISION2020 is a global initiative of the International Agency for the Prevention of Blindness, whose mission is the elimination of avoidable blindness by the year 2020. This will require the coordinated effort of all stake holders, and ongoing commitment from Ministries of Health. The key elements of VISION2020 are a) strategies for the control of the major blinding eye diseases (cataract, trachoma, onchocerciasis, blindness in children, refractive errors, and low vision), b) infrastructure development and supplying and maintaining equipment, c) human resource development, and d) community participation. Blindness from ROP is recognised as a priority for control in Latin America and Eastern Europe.

Globally there are estimated to be 60,000 children who are blind from ROP – Latin America being the region with the largest number (25,000). ROP is also an important cause of blindness in the Former Socialist Economies of Eastern Europe (24,000), and is emerging as an important cause in cities in Asia. Blindness due to ROP is likely to increase in India and China (home to 1/3 of the worlds population) as their economies improve, and neonatal intensive care services expand.

Revisions to the International Classification of ROP (ICROP). Dr Graham Quinn.

The first international classification of ROP has recently been revisited, and the following modifications have been made. The first modification is the inclusion in the classification of “aggressive, posterior ROP” (AP-ROP). This uncommon form of ROP, which occurs in zone 1 or posterior zone 2, is characterised by plus disease without *prominent* proliferative retinopathy; the neovascularisation is characterized by a flat, tangled web of vessels which typically extends circumferentially, and may be deceptively featureless. This form of ROP progresses rapidly to Stage IV or V. Secondly, an additional category describing abnormal tortuosity and/or dilation of retinal vessels at the posterior pole (“pre-plus” disease) is now included in the classification. Pre-plus disease is defined as “abnormal dilation and tortuosity of posterior pole vessels involving two or more quadrants, but insufficient for the diagnosis of plus disease”. Finally, a clinical method for determining whether disease is in zone 1 is described: when viewing the retina by indirect ophthalmoscopy with a 28D lens, if ROP is visible when the image of the disc is located at the periphery of the field of view, the disease is in zone 1.

Criteria for ROP screening programmes. Dra Clare Gilbert

In industrialized countries the population of premature babies at risk of threshold ROP has changed over time, and nowadays severe ROP almost exclusively affects extremely premature babies (i.e. those with birth weights (BW) <1,000 gms). In these countries screening is only undertaken on babies with BWs <1,500 gms, and gestational age (GA) criteria are <32, <31, or <29 weeks. More mature babies are only examined at the discretion of the neonatologist. However, data from middle and low income countries suggest that babies with “first epidemic” characteristics are also developing severe ROP. The implications of this are that larger, more mature babies should be included in screening programmes, to ensure that no baby needing treatment is missed. Criteria adopted in Latin American countries vary (e.g. <1,900 gms in Ecuador; <2,000gms in Peru), and given the fact that GA data are often unreliable, BW criteria tend to be relied on more than GA. The important message is that screening criteria developed for use in neonatal intensive care units in the USA or Western Europe may not apply in situations where neonatal care may not be so good. Ideally screening criteria should be based on data obtained by careful monitoring of data from screening programmes.

Update on results of Early Treatment Trial. Dra Luz Gordillo

In this large, multicentre clinical trial, babies were randomly allocated to early laser treatment (i.e. treatment when “high risk” prethreshold disease was present), or delayed treatment (i.e. treatment was only given if threshold disease developed). The outcomes were assessed at 9 months: i.e. visual acuity, structural findings, and complications during treatment. The findings of the trial were that babies treated earlier had better functional and structural outcomes than babies treated at threshold, but there were higher rates of ocular and systemic side effects in the group treated earlier. As a result of this trial the following are recommended

Treatment for babies with Type 1 pre-threshold ROP:

- Zone 1, any ROP with plus disease (≥ 6 hours)
- Zone 1, Stage 3 ROP +/- plus
- Zone 2, Stages 2 or 3 with plus disease (≥ 6 hours)

Frequent follow up of babies with Type 2 pre-threshold ROP:

- Zone 1, Stages 1 or 2 without plus
- Zone 2, Stage 3 without plus

The implications of this trial for ROP programmes are that more babies will need to be treated; they will be treated at an earlier age, and systemic complications are more likely, and more frequent follow up will be required for babies with Type 2 pre-threshold ROP.

Management information systems for ROP for ophthalmologists. Dr D Medina

In Bogota, Columbia, there are 12 NICUs where screening for ROP is taking place, but treatment is only available in one unit. There is a need to collect information in a standardised format, which is entered into a standardised database. Such a system would allow provide useful epidemiological data at a national, regional and neonatal unit level; and could provide the following information: the number of babies being screened and rates of the different stages of ROP; data on risk factors for prethreshold and threshold disease; criteria for screening could be monitored; the outcome of treatment (anatomical and functional) could be evaluated; long term follow up data could be made available (e.g. on refractive errors and visual acuity). The data collection form and database in use on Bogota were demonstrated. There are logistical challenges in implementing such a system, which requires extra work for data entry, as well as quality control and supervision. However, there are considerable advantages in having a system which allows the whole programme to be monitored and evaluated.

Management information systems for ROP for neonatologists. Dra Anna Villanueva

In Peru an excellent database has been set up for monitoring all admissions, morbidity and mortality among babies admitted to NICUs in the Social Security System throughout the country. The system was set up as a monitoring tool, with a view to improving neonatal care throughout the country. The database was demonstrated. Setting up and running the database has taken a great deal of work, with visits to the units, but data recording has improved, the data are now collected in a standardised manner, which allows trends to be monitored, and as a result neonatal outcomes have improved.

Health education materials for parents. Dra Luz Gordillo

Parents play a key role in ensuring that their child grows up with as good a visual acuity as possible. They need to know about the need for screening, particularly once their baby has been discharged from the NICU, the need to return after treatment, and that long term follow up may be required to detect and manage late complications such as refractive errors and strabismus. A range of different approaches can be used, ranging from posters, pamphlets and cartoons, through to videos, group sessions with nurses or trained volunteers, and one to one discussion. The health education material developed should take account of the fact that mothers are often very young, with poor literacy skills. Annual parties can also be very motivating for parents and enjoyable for children. Dr Gordillo demonstrated some of the educational materials that have been developed for use in Lima.

Need for follow up of premature babies. Dra Andrea Zin

Premature babies are at increased risk of significant refractive errors, particularly myopia, strabismus and amblyopia compared with full term babies. They may also have visual impairment from ROP as well as from lesions of the higher visual pathways (optic nerve, visual cortex, and higher association areas). The risk of non-ROP pathology is associated with a) lower gestational age b) development of acute ROP c) cerebral palsy d) abnormal ultrasonic brain scans in early life. Strabismus can affect up to 25% of premature babies, which rises to almost 40% in extremely low birth weight babies. The following is recommended for follow up after the acute phase of the retinopathy is completed:

All prematurely born infants with GA < 32 weeks should be followed up by a pediatric ophthalmologist. Babies receiving cryo/laser are particularly at risk. The follow-up schedule selected will depend on available resources:

Number of follow ups possible	Timing of 1 st examination*	Timing of 2 nd examination*	Timing of 3 rd examination*
1	12 months*	NA	NA
2	12 months	24-30 months	NA
3	12 months	24-30 months	42-48 months

*corrected age

Low vision care for premature babies. Dra Celia Nakanami

Currently there are inadequate low vision services for children who have the potential to benefit in Latin America. Low vision care for children differs from that in adults because of the risk of developmental delay, and because a child's visual system is developing and changing. Indeed, even in normal children the visual acuity improves from 20/260 at 2 months, to 20/600 at 12 months, to approximately 20/20 at 4 years. Parents are also key to the success of visual rehabilitation of children and need to be included as a key component, and other professionals (e.g. teachers) also need to be involved. Many premature infants who have visual impairment have associated multiple other disabilities (sensory, motor and cognitive developmental delays) which compounds their developmental delay.

Ideally children with ROP should be followed up by a Pediatric Ophthalmologist or Ophthalmologist at least until the child is 3 years old, because of the risk of other eye problems (retinal detachment, myopia, amblyopia, strabismus, glaucoma) and so that children with visual loss can be referred for visual habilitation /rehabilitation (early visual stimulation and Low Vision care) services and their family for advices. The following table shows childrens' reading ability in relation to their distance visual acuity:

A. Classification of Vision Loss (WHO/ICO)			B. Performance Ranges for Reading Tasks
(Near) normal vision	Range of normal visual acuity	20/12 16 20/20 25	Normal reading performance Normal reading distance
	Near-normal visual acuity	20/30 40 50 60	Normal reading performance Shorter reading distance
Low vision	Moderate visual acuity loss	20/80 100 125 160	(Near-) normal performance, using magnifiers, other aids
	Severe visual acuity loss	20/200 250 300 400	Slower than normal reading, using magnifiers, other aids
	Profound visual acuity loss	20/500 600 800 1000	Limited reading with high-power aids, videomagnifier Also relies on substitution: talking books, Braille
(Near) blindness	Near-blindness	20/1250 1600 2000 2500	Detail vision unreliable Relies on readers, talking devices
	Total blindness	NLP	No detail vision possible

Being able to reach development mile stones is also dependent on good vision, as seeing and reaching for objects is an important part of the process of development. The following table shows how to assess a child's visual function.

0-1 mo	Moving the head to the light/ visual contact 6- 8 weeks
2-3 mo	Intense visual contact/mobiles interesting/human face interesting
3-6 mo	Aware of hands / reaching objects/changing fixation/ observing moving toys
7-10 mo	Perception of small objects/recognition of partially hidden objects
11-12mo	Visual orientation at home/ recognition of the people/figures

Early identification is very important, as early intervention (which should include early visual stimulation) leads to better outcomes. Ideally a multi-disciplinary team should be involved, including an occupational therapist, physiotherapist, and psychologist. Visual stimulation includes the use of materials and objects that are of high contrast and brightly coloured. Other senses, such as touch and hearing, should also be used. Parents play a vital role in the process, and should be included as key to children learning compensatory skills and adaptive behaviours. .

Older children need support that will enable them to access as normal an education as possible. Additional inputs will be required so they can acquire skills (and hence independence) in orientation and mobility; activities of daily living; how to use glasses and low vision devices. They may also need psychological support, vocational training, and may need be taught how to read and write Braille.

The essentials of low vision care for children entail optical and non-optical components:

- Adequate magnification at a suitable working distance
- Good illumination
- High contrast
- Motivation in the use of devices

SUMMARY OF DISCUSSIONS SESSION 1: Constraints and challenges

In this group work 7 groups were formed, of two or more countries per group. Ophthalmologists and neonatologists from the countries worked together. The purpose of this group work was for participants to analyse the situation in their own country to identify constraints, and also so they could learn about programmes in other countries represented in the group.

Ecuador and Peru:

Common problems:

Neonatologist

- 1) Insufficient trained human resource
- 2) No standardization of procedures
- 3) Insufficient equipment and inadequate maintenance

Ophthalmologists

- 1) Insufficient equipment.
- 2) Poor data collection
- 3) Variable follow up in outpatient

Problems unique to Ecuador

- 1) Lack of patient reference

Problems unique to Peru

- 1) Lack of equipment
- 2) Difficult to obtain operating room
- 3) Lack of paediatric anaesthetist

Actions

- 1) Education (parents, neonatologists, ophthalmologist, community)
- 2) To trainee personal involved
- 3) Equipment (particular. Government , NGO)

Argentina, Uruguay and Paraguay

Common problems:

- 1) Great disparity in neonatal care
- 2) Lack of resources for screening
- 3) Lack of motivation, high legal risk, low remuneration
- 4) Lack of legal framework

Problems unique to Argentina

- 1) Inadequate networks
- 2) Concentration of resources

Actions

- 1) Obtain resources to sustain training initiatives over time
- 2) Create unified data registry

Guatemala, El Salvador, Honduras, Nicaragua

Common problems

- 1) Lack of statistics
- 2) Lack of national policies
- 3) Lack of national committee
- 4) Lack of budget allocation
- 5) Low awareness/education
- 6) Technology/equipment for screening and treatment

Unique problems

- 1) There is no screening program

Actions

- 1) Create database → statistics
- 2) Promote a common protocol
- 3) Awareness raising/education: parents, paramedics, doctors (ophthalmologists, neonatologists, pediatricians)
- 4) Audiovisual material
- 5) Raise awareness (detection, treatment, follow-up)

Bolivia and Chile:

Common problems

- 1) Transportation
- 2) Improve skills and train in ROP diagnosis

Problems unique to Bolivia

- 1) There is no government support
- 2) Low survival: 0% <750g; 30% 750-1500g
- 3) ROP still mainly in babies 1500-2000g
- 4) There is no recording system

Actions Bolivia

- 1) Implement screening in the 5 Intensive Care Units (25 beds): requires ophthalmoscopes and human resources
- 2) Implement mobile laser treatment using in public center
- 3) Implement data recording system

Problems unique to Chile

- 1) Improve survival in infants <750g (29%)
- 2) Lower incidence of ROP in infants 1,250-1,500g (16 percent)

Actions Chile

- 1) Improve transportation
- 2) Improve screening in the national network to optimize transportation
- 3) Develop real-time recording system

Brazil and Mexico

Common problems

- 1) Demographic problems
- 2) Lack of national policy on ROP
- 3) Economic and personnel limitations
- 4) Inadequate neonatal care
- 5) Lack of epidemiological information

Problems unique to Brazil

- 1) Cultural diversity and diversity of care
- 2) Problems (coverage) in improving detection and treatment programs
- 3) Lack of visual rehabilitation programs

Problems unique to Mexico

- 1) Lack of knowledge about the illness
- 2) Programs' coverage is limited
- 3) Lack of resources (human and material)

Actions

- 1) Dissemination of information among medical community and authorities (three months)
- 2) Enhance and expand existing programs

Colombia and Venezuela

Common problems

- 1) Screening is *ad honorem*
- 2) Lack of follow-up
- 3) Very few people trained in screening and treatment
- 4) Inadequate gathering of data for analysis, and lack of statistics for planning
- 6) Lack of security for treatment (anesthesia, post-operative care)
- 7) No government participation (health policies)
- 8) Lack of oversight of quality of unit

Problems unique to Venezuela

- 1) No equipment for treatment
- 2) There are screening programs, but no possibilities of treatment, with respective ethical and medical-legal implications

Problems unique to Colombia

- 1) Patients referred by insurers to other centers that do not have experience
- 2) Internal conflicts among ophthalmologists, pediatricians and retinologists
- 3) Lack of trained ophthalmologists (wages)

Actions

- 1) Create unified data-gathering system
- 2) Standardization of criteria
- 3) Continuing medical education (web)

- 4) Obtain funds for ophthalmologists dedicated to screening and treatment
- 5) Prenatal prevention and outreach campaigns

Costa Rica, Cuba, Panama, Dominican Republic

Common problems

- 1) Enough ophthalmologists, but centralized
- 2) Late referral: relative in Costa Rica and Cuba, somewhat in Panama, always late in the Dominican Republic
- 3) Low Vision: exists in Costa Rica, the Dominican Republic and Cuba, but not in Panama
- 4) Laser treatment in Costa Rica, cryo only in Panama, laser and cryo in the Dominican Republic and Cuba
- 5) Laws and protocols exist in Costa Rica and Cuba, but not in Panama or the Dominican Republic

Actions

- 1) Establish national norms in Panama and the Dominican Republic
- 2) Computer system in Cuba
- 3) Follow-up network
- 4) Awareness raising

SUMMARY OF GROUP WORK: SESSION 2. Specific actions to increase coverage of ROP screening programmes:

Argentina:

Within 2 months:

1. Register private intensive neonatal therapy units
2. Letter asking whether there is screening and name of ophthalmologist

Within 1 year:

3. Continue advising public/private sector: neonatal care standards
4. Equipment: saturoimeters and ophthalmoscope.
5. Identification of high-risk pregnancies

Bolivia:

2 months:

1. Reactivate national ROP committee
2. Presentation: National ROP Plan to obtain funding
3. Acquire indirect ophthalmoscopes and laser
4. Training/coordination of joint activities (ophthalmols-neonatologists) based on new equipment

1 year:

5. Continue screening program
6. Encourage and motivate other intensive care units
7. Involve more ophthalmologists and neonatologists
8. Evaluation of outcomes
9. Information for parents, ophthalmologists, neonatologists, nurses according to national plan.

Brazil:

What

Increase and disseminate information (catalyst for change) to

- Managers: introductory kit for financial and legal managers
- INCU teams (neonatologists, nurses, ophthalmologists, physical therapists, social workers): these will need to be specific
- Societies (scientific and civil): information on medical fees, civil responsibility
- Families: films and posters

Who

"ROP Brazil" working group (CRN, RMG, NG, TF)

When

December 1, 2005 Workshop with 40 people

February 2006-final

Why

- To define strategies based on information
- To enhance screening programs
- To improve low vision program

Chile:

1. Review and update clinical guide
2. Distribute parents' guide through neonatal network
3. Distribute diagnostic guide poster through network
4. Develop indicators for evaluation of outcomes: process and quality of care

Colombia and Venezuela

1. Publication December 2005 national
2. Appointment with Ministry of Health, societies: scientific organizations and PAHO (JCS)
3. Develop training curriculum for residents (UV Zuluga, U Zabena, U Rosano, Central de Venezuela-Raiza Rojas, U. Zulia Nelio Urdanet)
4. Complete edition of neonatology magazine on ROP (Dr. Bastidas/R. Rojas, thr Ven. Society)
5. Academic activity in regional branches of neonatology society (SCON, SVO)
6. Locate high-risk units in Cali and Bogotá, David Medina)
7. Training for human resources
8. Obtain resources for prevention and promotion in Venezuela

Costa Rica:

2 months:

1. Create 2 more screening centers
2. Hold a national ROP workshop
3. Obtain support staff for gathering data and information from parents
4. Creation of national committee

1 year:

5. Complex computerized control
6. Norms updated and implemented
7. Integration/expansion of treatment coverage
8. Present information on ROP in congresses for neonatologists/ophthalmologists

Cuba

2 months:

1. Create 2 more screening centers
2. Prepare national ROP workshop

1 year:

3. Expand coverage
4. Improve data gathering
5. Hold workshops

Dominican Republic:

2 months:

1. Initial pilot screening program
2. National awareness-raising campaign

1 year:

3. National dissemination of information – screening centers

Ecuador:

1. Periodic meetings:
 - a. of national committee
 - b. of ROP Ecuador
2. Raise public awareness nationwide:
 - a. information in media
 - b. doctors, parents and community
 - c. visit to neonatal units

El Salvador

2 months:

1. Reinforce communication with peripheral hospitals (Rottman)
2. Develop database (Ramirez)
3. Establish inter-institutional cooperation for treatment
4. Share statistics to develop common national report (Rottman and Ramirez)
5. Develop informative brochure for parents (Rottman and Ramirez)

1 year:

6. Develop and National policy and seek funding

Guatemala

2 months:

1. Make contact with units without a program HGSJD (Sanchez)
2. Demonstrate to neonatologists / pediatricians the existence of the problem (Sanchez/ Aguilar)
3. Develop common data-gathering form (Sanchez)
4. Monthly meeting to monitor goals and objectives (Aguilar)

1 year:

5. Expand screening coverage from 28% - 40%

Honduras

2 months:

1. Promotion with Neonatology-Pediatrics (Mejia)
2. Involve ophthalmologist and pediatrician in program planning
3. Contact ophthalmologists in hospitals with NCUs

1 year:

4. Inter-institutional cooperation (JUSP)
5. Funding
6. Creation of screening program a. Data gathering b. Diagnosis and treatment

Mexico

1. Dissemination of information to authorities, Secretary of Health, and AMR- SSA (MAF; JCB)
2. Education e.g. presentations at national Congress 2006; day of sub-specialty; trans-congress course; annual meeting AMR, MAF, JCB
3. Identify the number of IUCNs in country (RPC)
4. Data: create a single format, and a database (neonatologists and ophthalmologists 32 states)

Nicaragua

2 months:

1. Develop work plan with neonatologists (Salvatierra)
2. Disseminate ROP statistics
3. Integration of neonatal units
4. Contact director of national ophthalmology center to assign an ophthalmologist for screening

1 year:

5. Seek funding
6. National policy (governmental)

Panama :

2 months

1. Create 2 more screening centers
2. Workshop with national committee (neonatologists, ophthalmologists, pediatricians, retinologists)
3. Initiate national norms
4. Disseminate information about ROP among pediatricians and ophthalmologists

1 year:

5. Implement national norms
6. To include national ROP network

Paraguay:2 months:

1. December meeting: ophthalmologists/neonatologists coordinating actions

1 year:

2. Regionalize screening metropolitan Asunción
3. Assign responsibility to institutions
4. Workshop for nurses at Paraguayan Congress of Ophthalmology

Peru

1. Identify neonatal units in country with >2,000 live newborns
2. Hold national level workshop in 2006
3. Form national ROP committee, comprising ophthalmologists, neonatologists, visual rehabilitation specialists, delegates of Minsa-Peruvian Ophthalmology Pediatrics Societies.

Uruguay:2 months:

1. Obtain funding for screening/in public units

1 year: (Martinotti)

2. Obtain 1 laser for Pereyra Rossell Hospital: only treatment center,
3. Implement national plan

CONCLUSIONS AND RECOMMENDATIONS

1. ROP as a cause of blindness:

Conclusion	ROP is an important cause of blindness in children in the region. In some countries the proportion of blindness due to ROP is increasing. However, not all countries have data on the causes of blindness in children.
Recommendation	<ol style="list-style-type: none">1. There is a need to collect these data where they are currently not available, and, if possible, to repeat data collection every 10 years, to monitor trends over time2. Ideally the World Health Organization's Prevention of Blindness methodology and classification should be used, so that data are comparable between countries and over time3. These data need to be published and presented at meetings, to increase awareness of the problem of ROP blindness

2. Situation analysis:

Conclusion	Some countries, but not all, have a clear idea of the extent of their screening programmes, and the degree to which the need is currently being met.
Recommendation	That a situation analysis be undertaken in countries to provide information on the number of units in the country, and the provider; the number of preterm babies at risk, and the extent to which the screening programme is meeting this need. This information is essential for planning.

3. Increasing coverage:

Conclusion	There are many challenges to increasing coverage of ROP programmes. Lack of financial reimbursement for time spent by ophthalmologists on the programme is a major factor
Recommendation	<ol style="list-style-type: none">1. Countries in the region with well established programmes can assist those countries where programmes have only just started, particularly in terms of training in screening and treatment. This could be done through a well developed plan of ongoing support and partnership.2. To develop sustainable programmes, government support is required. This will require advocacy and lobbying.

4. Follow up of premature babies:

Conclusion	Late sequelae (ophthalmological and systemic), are much more common in premature than in full term babies. Long term follow up of premature babies regardless of ROP status, is therefore required, to identify and manage problems, some of which are sight threatening.
Recommendation	<ol style="list-style-type: none">1. Appropriate, realistic guidelines need to be developed, to make sure babies most at risk are followed up2. Health education and awareness of the need for follow up should be included in information for parents3. Planning and advocating for paediatric and ophthalmological services for long term follow up should be part of ROP programmes

5. Guidelines:

Conclusion	Most countries are following similar policies and practices for screening and treatment
Recommendation	That regional guidelines be developed by neonatologists and ophthalmologists, under the auspices of the IAPB, PAHO, PAAO and SIBEN, which can be used (after modification, if required) not only for programme implementation, but also for advocacy and to mobilise resources. A working group will be formulated to work on this, with support from CBM.

6. Awareness:

Conclusion	Many countries have produced health education materials for parents, the general public, and for health care providers (neonatologists and eyecare
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providers). However, more still needs to be done to increase the profile of ROP in many countries.

- Recommendation
1. Countries need to make sure that raising awareness is explicitly included in their programmes. This can be achieved through publications, the mass media etc.
 2. Given the common language throughout the region, educational materials should be made widely available, possibly through the IAPB website.
 3. Different aspects of ROP and ROP control programmes need to be included in the curriculae of nurses, ophthalmologists, pediatricians and neonatologists.
 4. Continuing medication education for ophthalmologists and neonatologists should also include ROP.

7. Monitoring and evaluation of programmes:

Conclusion Each country needs to decide the minimum essential information needed to monitor and evaluate their programme, from the perspectives of coverage, and quality.

Recommendation That a standard reporting form, database, and statistical package be used throughout the region, if possible.

8. Regional neonatology group:

Conclusion Meticulous neonatal care is essential for preventing ROP

Recommendation That a regional group of neonatologists be formed, to address issues of relevance to the prevention of ROP.

9. Communication:

Conclusion Sharing of information of relevance to all aspects of ROP and its control is important in preventing the disease and improving programmes.

Recommendation That a site be prepared on the IAPB website for the ROP regional group, as a mechanism for sharing ideas, and discussing problems and their possible solution.

10. Output of workshop:

Conclusion Each country identified key activities to be undertaken over the next 3 months, and over the next 12 months.

Recommendation That progress in undertaking activities assigned at the Lima meeting in November 2005 be reported at the ICO meeting, Sao Paulo in February 2006.

APPENDIX 1

Programme

Regional workshop on ROP for Latin America Nov 14-16 2005 Lima, Peru

Purpose:

To increase the coverage of effective screening and treatment programmes for ROP in Latin American countries

Objectives:

To review constraints and barriers and how they can be overcome in order to

- Increase awareness of the need for screening among all stakeholders
- Increase coverage of screening programmes
- Improve diagnosis of ROP
- Improve treatment outcomes
- Ensure good follow up in low vision and paediatric clinics, as required

Output:

Draft guidelines on all aspects of ROP screening and treatment, to include neonatal and ophthalmologic components

Supported by Christoffel Blinden Mission

Alcon Ltd.

Opton Ltd.



Faculty:

Dra Luz Gordillo, Peru
Dra Andrea Zin, Brazil
Dr Juan Carlos Serrano, Colombia
Dra Clare Gilbert, UK
Dr Graham Quinn, USA

Day 1 Monday November 14th 2005

9:00	Welcome and Introduction		President of Peruvian Oph.
9:15	Objectives of the Workshop		L Gordillo
9:25	Activities of IAPB Childhood Blindness Committee		A Zin (Chair of Committee)
9:30	Vision 2020 and ROP as a cause of blindness		C Gilbert
9:45	Update on classification of ROP		G Quinn
10:00	Screening criteria		C Gilbert
10:15	Update on results of Early Treatment Trial		L Gordillo
10:30	<i>Coffee break</i>		
	Current ROP screening programmes:		
11:00	Argentina	Dr. Julio Urrets and Dr. Julio	Hauviller/Galan/Benitez
11:20	Bolivia	Dr. Gustavo Aguirre	Jijena
11:40	Brazil	Dr. Celia Nakanami	Zin/Florencio/Graziano/Giani
12:00	Chile	Dr. Alejandro Vazquez de Kartzow	Morgues
12:20	Colombia	Dr. Juan Carlos Serrano	Zuluaga /Medina/Bastidas
12:40	Costa Rica	Dr. Mariana Vargas	
1:00	<i>Lunch break</i>		
2:00	Cuba	Dr. Mayra Mier	Toledo/Morilla
2:20	Peru	Dr. Martin Midzuaray	Colleagues
2:40	<i>Tea break</i>		
3:00	<u>Group work session 1 with feedback</u> 1. What are the limitations of <u>current</u> screening programmes? 2. How could these be overcome? 3. What concrete steps can be taken to improve the quality of <u>current</u> screening and treatment programmes?		
4:30	Group feedback		

Day 2 Tuesday November 15th 2005

Current ROP screening programmes (continued):			
9:00	Dominican Rep.	Dr. Juan Ubiera	
9:20	Ecuador	Dr. Renato Semiglia	Almeida / Pacheco
9:40	El Salvador	Dr. Loly Ramírez	Ramírez /Rottmann
10:00	Guatemala	Dr. Lisette Aguilar	Aguilar/Sanchez
10:20	Honduras	Dr. Diego Mejia	
10:40	<i>Coffee break</i>		
11:00	Mexico	Dr. Carlos Bravo Dr. Marco de la Fuente	Bravo /de la Fuente / Perez
11:20	Nicaragua	Dr. Amelia Salvatierra	
12:00	<u>Group work session 2:</u> 1. What are the constraints / barriers preventing screening programmes being developed in <u>all</u> units caring for premature babies at risk? 2. How can these be overcome? 3. What concrete steps can be taken to improve coverage?		
1:00	Lunch		

2:00	<p><u>Group work session 3a with feedback - ophthalmologists:</u> Can a standard protocol / best practice guidelines be developed for the region on:</p> <ol style="list-style-type: none"> 1. Information given to parents by ophthalmologists 2. Screening criteria 3. Timing, method, frequency and place of examinations, and ensuring follow up 4. Indications and consent for treatment 5. Method of treatment, and follow up after treatment 6. Training in examination and treatment 7. Follow up of premature babies 8. Referral to low vision / rehabilitation for children with visual impairment from ROP 9. Data to be collected for monitoring and evaluating programmes <p><u>Group work session 3b with feedback - neonatologists:</u> Can a standard protocol / best practice guidelines be developed for the region on:</p> <ol style="list-style-type: none"> 1. Minimal acceptable standards for oxygen monitoring 2. Information given to parents by neonatologists with respect to ROP 3. Identifying and recording babies needing examination (who and how) 4. Care during examination in intensive care 5. Ensuring discharged and treated babies attend for follow up 6. Care during laser/cryo treatment 7. Follow up of premature babies by paediatricians 8. Data to be collected for monitoring and evaluating programmes
3:30	Tea break
4:30	Feedback

Day 3 Wednesday November 16th 2005

Current ROP screening programmes (continued):			
9:00	Panama	Dr. Roberto Yee	
9:20	Paraguay	Dr. Pablo Cibils	Pineda
9:40	Uruguay	Dr. Leonora Martinotti	Manzanares
10:00	Venezuela	Dr. Pedro Mattar	Rojas
10:20	Coffee break		
11:00	Management information systems for ROP		
	- for neonatologists		D Medina
	- for ophthalmologists		A Villanueva
11:30	Health education materials for parents		L Gordillo
12:00	Need for follow up of premature babies		A Zin
12:30	Low vision care for premature babies		C Nakanami
1:00	Lunch break		
2:00	<p><u>Group work session 4 with feedback:</u> How can countries collaborate in terms of</p> <ol style="list-style-type: none"> 1. Training in examination and treatment? 2. Management information systems? 3. Planning, monitoring and evaluating programmes? 4. Information for parents and providers? 5. Advocacy and information for policy makers? 		
4:00	Feedback		
5:00	Conclusions and recommendations		

APPENDIX 2. Draft guidelines for ROP programmes in Latin America

This came out of the Workshop session 3, in which participants were divided into groups. They were asked to discuss and make recommendations concerning the following areas:

Ophthalmologists:

- 1) Group 1
 - a. Information given to parents by ophthalmologists
 - b. Screening criteria
- 2) Group 2
 - a. Timing method, frequency of examinations, and ensuring follow-up
- 3) Group 3
 - a. Indications and consent for treatment
 - b. Method of treatment and follow up after treatment
- 4) Group 4
 - a. Training in examination and treatment
 - b. Follow-up of all premature infants
 - c. Referral to low vision/rehab programs for children with visual impairment from ROP
- 5) Group 5
 - a. Data to be collected for monitoring and evaluating programs

Neonatologists:

Can standard protocol/best practice guidelines be developed for the region on:

- 1) Group 1
 - a. Minimal acceptable standards for oxygen monitoring
 - b. Information given to parents by neonatologists with respect to ROP
 - c. Identifying and recording of babies needing examination (who and how)
 - d. Care during examinations in intensive care
- 2) Group 2
 - a. Ensuring discharged and treated babies attend follow-up
 - b. Care during laser/cryo treatment
 - c. Follow-up of premature babies by pediatricians
 - d. Data to be collected for monitoring and evaluating programs

DRAFT REGIONAL GUIDELINES FOR ROP SCREENING AND TREATMENT PROGRAMMES IN LATIN AMERICA

1. Neonatal care:

To reduce the risk of ROP:

Minimal acceptable standards for monitoring of oxygen:

- Personnel trained during procedure of administration of oxygen.
- Adequate equipment must be available (e.g. pulse oximeter) to monitor all babies receiving supplemental oxygen
- Adequate blenders and heater humidifiers must be available
- Maintain oxygen saturation between 88% and 92% and monitor arterial oxygen between 70 and 80 mmHg

2. Information:

For parents:

The following information should be provided to all parents of babies at risk of ROP:

- A description of the maturing process of the retina
- Risks to the maturing retina from prematurity, illnesses and therapies.
- Possibility of preventing blindness with timely diagnosis and treatment, and what this will entail
- Importance of timely examinations, even if baby is discharged from NICU

3. Screening:

Criteria

The following criteria were suggested:

- Birth weight: $\leq 1,750$ gs and/or
- Gestational age ≤ 32 weeks.
- Birth weight $>1,750$ at the discretion of the neonatologist

However, as the risk of ROP in any NICU is related to case mix as well as neonatal outcomes and levels of care, NICUs may want to set their own criteria. This should be done on the basis longitudinal studies of at least one year in which details of the BW, GA and eye findings of consecutive babies are recorded.

It is the responsibility of the neonatologist to identify those babies who should be examined, to keep a diary for determining when the first examinations are needed, and to notify the ophthalmologist of the need for ROP screening examinations in a timely manner.

Timing and frequency

When a reliable estimate of gestational age is not available, the first examination should be 4-6 weeks after birth

For babies with a reliable estimated gestational age of at least 28 weeks, examinations should begin at 4-6 weeks after birth. As neonatal care improves and increasingly premature babies survive, these guidelines may need to be modified (see below).

Gestational age	Timing of first examination	Post-gestational age
≥ 28 weeks	4-6 weeks	32-34 weeks
27	4	31 weeks
26	5	31 weeks
25	6	31 weeks
24	7	31 weeks
23	8	31 weeks

Subsequent examinations:

- If the retina is immature and there is no ROP, the next examination should be at 2 - 3 weeks
- If there is ROP in zone 3, the next examination should be at 2 weeks
- If there is ROP zone 1 or 2 the next examination should be at 1 week, or at 3-4 days depending on the stage of disease and the appearance of the posterior pole vessels
- Examinations should continue until the retina is fully vascularized (within 1 disc diameter of the ora serrata) or the ROP has regressed

It is the responsibility of the ophthalmologist to decide when the next examination should be, to inform the neonatologist caring for the baby if the child is an inpatient or the mother/parents if the child is an outpatient, and to document the date for the next visit.

If, in the opinion of the neonatologist, the infant is too unstable to undergo the eye examination at the interval suggested by the ophthalmologist, the reason for the delay should be documented in the infant's chart.

Methods:

Pupil Dilatation:

Cyclopentolate 0.5 % combined with phenylephrine 2.5% or Tropicamide 0.5%. All mydriatic eyedrops should be instilled at least 30 minutes or 1 hour prior to examination.

Retinal examination:

Indirect ophthalmoscopy with a 28 or 30 D lens is recommended, after fully dilating the pupils. Instillation of topical anaesthetic is strongly recommended if a lid speculum is being used. The examination should be performed by an ophthalmologist experienced in diagnosis of ROP. The examiner should first examine the posterior pole, to look for signs of vascular dilation and/or tortuosity (pre-plus, or plus disease), and then examine the nasal retina and then the temporal retina to determine the zone of vascularization and stage of retinopathy if present.

Place of examination:

If the baby is still on the NICU, the baby should be examined in the NICU at the appropriate postnatal age, regardless of whether the baby is in an incubator / being ventilated.

After discharge the baby should be followed up as an outpatient either at the NICU or in the ophthalmologist's office.

Support during examination:

Before scheduling an ROP screening examination, the neonatologist should check that the baby on the NICU is stable enough to be examined.

A neonatologist must be available during screening in case a baby develops cardiovascular or respiratory problems.

Ensuring follow up:

- The NICU should collect detailed addresses and telephone numbers (including those of parents and other relatives) for each baby so they can be easily contacted for follow up examinations.
- Every effort should be made to ensure timely follow up. This might include telephoning, or by requesting personnel health assistant, or social workers to contact the family

4. Treatment

Indications

Threshold disease: Stage 3 with plus disease affecting 5 hours contiguous or 8 or more cumulative clock hours in zone 1 or zone 2

Or

Type 1 pre -threshold disease (ET-ROP definition:

Zone 1 any stage

Zone 2 Stage 2 + plus

Zone 2 Stage 3

Stage IVa and Stage IVb:

Vitreoretinal surgery may be indicated for Stage IVa or b, but the decision to operate, and the nature of the surgical intervention, needs to be based on a careful assessment of the eye, and of the child, by an experienced vitreoretinal surgeon, in collaboration with the anaesthetist, and paediatrician.

There are no internationally agreed guidelines concerning the timing of treatment, nor evidence from clinical trials as to which are the optimum interventions.

Stage V: Complex vitreoretinal surgery is not recommended, as the functional results are generally extremely poor even in anatomically successful results (add references from CRYO-ROP and other studies).

Consent

Written, informed consent should be obtained from the parents / guardian, using an information sheet that is easy to understand.

Methods

360-degree ablation of the peripheral avascular retina, treating anterior to any ROP, should be by laser and/or cryotherapy.

Care during treatment:

The patient should be prepared and monitored during the entire procedure by the neonatal nurse, neonatologist and/or anesthesiologist. The procedure should be done in an operating room or appropriate care sector. The choice of sedation, analgesic or general anesthetic will depend on the possibilities of each service. Post-treatment recovery should be done in the neonatal intensive care unit.

Follow up after treatment

After treatment the baby should be re-examined at 1 week. Untreated areas should be looked for, as well as signs of regression / progression of ROP and/or of plus disease. Postoperative ocular medications might include steroid/antibiotic combinations for a week to 10 days.

Indications /methods for retreatment

The peripheral retina should be retreated with laser or cryotherapy if there are signs of progression. In general, retreatment of skip areas is needed only if there is progression. Careful observation for progression to retinal detachment is needed in the postoperative weeks.

5. Training in examination, diagnosis and treatment:

For screening

Training for a general ophthalmologist who already knows how to do indirect ophthalmoscopy: at least twice a week for 3 – 6 months, examining at least 100 cases with an experienced screener.

For treatment

The person should have observed at least 10-15 treatments and should begin to provide treatment under expert supervision.

6. Follow-up by pediatricians:

If the patient was not included in a follow-up program after leaving the NICU and was to be followed up by a general pediatrician, the pediatrician should be contacted and adequately informed of the child's situation including need for long term evaluation for amblyopia, strabismus and high refractive error

7. Follow-up by ophthalmologists:

- For babies with Stage 3 ROP or who have been treated for ROP: Regular checkups until preschool age because of a higher incidence of problems of refraction, myopia, strabismus, amblyopia and other ophthalmologic problems.
- For babies who were not treated: checkups until one year of age. The neonatologist should be responsible for arranging follow up with the ophthalmologist.

8. Low vision

Who to refer All premature babies whose corrected vision is less than 20/70 using recognition acuity, or who have poor fixation, should be referred to a low vision / rehabilitation program

9. Data for monitoring and evaluation:

Data to be compiled at country level: Number of newborns < 2000 g birth weight
Rate of premature babies surviving with < 2000 g birth weight
Number of Neonatal Intensive Units
Number of Units with ROP screening
Number of Unit that provide treatment for ROP
Number of premature babies screened
Number of premature babies treated
Birth weight and gestational age of babies treated

Data to be collected in each unit Date of birth
Sex
Birth weight
Gestational age
Days on oxygen and ventilation
Date of first eye examination
Date of last eye examination
Stage of ROP
Treatment given (laser, cryo, VR surgery), and outcome of treatment
Subsequent ophthalmologic checkups: at 6 and 12 months
If patient dropped out of program

Database: Ideally all the above data should be collected in a database, which is regularly updated, and which is accessible to all those involved in the management of neonates, as well as the ophthalmologists involved in screening and treatment.

10. Involving parents:

Parents play a critical role. The NICU discharge summary given to parents should ideally include details of dates of eye examinations, and what was found, and the date for the next examination