



## **IAPB VISION 2020 WORKSHOP**

**Regional ROP workshop, Barnaul, Altai region, Siberia, Russia**

**June 20<sup>th</sup> and 21<sup>st</sup> 2014**

Hosted by Altai Regional Ophthalmology Hospital

Local Organizer: Dr Vladimir Lebedev

Venue: Sanatorium Ob

***Funded by : Shreveport Sees Russia***



**Purpose:**

To support the development of regional ROP programmes in Russia through interactive seminars and presentations on best practice in ROP management.

**Objectives:**

Experience and expertise of the participants and facilitators will be used to:

- 1 Estimate the size and demographic characteristics of the population at risk of ROP
- 2 Increase awareness of the importance of antenatal steroids and high quality neonatal care for the prevention of ROP
- 3 Increase awareness of need for screening among all stake holders including pediatricians, neonatologists, nurses, ophthalmologists, and parents
- 4 Outline ideas to increase coverage of screening and treatment programmes
- 5 Outline ideas for improving current ROP programs
- 6 Identify ophthalmologists' training needs
- 7 Ensure good follow up in low vision and paediatric clinics, as required

**Output:**

- 1 Report summarising the recommendations and discussions in the seminars
- 2 A list of identified training needs

The day before the workshop the facilitators visited the neonatal intensive care unit and the Altai regional Ophthalmology Hospital in Barnaul.

## Day 1 June 20<sup>th</sup> 2014

Participants: Approximately 80 participants: ophthalmologists, neonatologists and neurologists from Barnaul and surrounding regions

### PLENARY SESSIONS

Dr Vladimir Lebedev, Regional Ophthalmologist for Siberia, welcomed participants. He explained that a meeting on ROP for the regional had taken place two years ago.

Professor Ludmilla Katargina outlined the current situation in Russia, explaining how the Ministry of Health has supported the development of programmes for the control of ROP which are fully integrated into the expanding services for care of sick newborns. Russia currently has 58 level 3 neonatal units for care of preterm infants and sick newborns, and 32 more are planned. Many RetCams and lasers have been purchased for the programme, and the new units will also have equipment for the diagnosis and treatment of ROP. Staff are being trained in Moscow and St Petersburg, and ROP programmes are expanding and improving across the country. In 2011 the Ministry of Health published national guidelines for ROP programmes which were developed by the Ophthalmological Society.

There have been several national conferences which have either included presentations on ROP, or which have exclusively focused on ROP in Moscow. This was the first multi-disciplinary workshop outside Moscow.

#### ROP as a cause of blindness. Professor Clare Gilbert

Earlier estimates of the number of children who were blind from ROP ten years ago, which used data from examining children in schools for the blind and blindness prevalence estimates, suggested that there were 50-60,000 blind children up to age 15 worldwide. A more thorough analysis has recently been undertaken, which used data from almost 900 publications between 2000 and 2010 and several meta-analyses, estimated that 32,300 children are becoming blind or visually impaired from ROP each year. The highest number is in Asia, and the lowest in Africa. In the Eastern European and Central Asian region, the rate of ROP blindness is 2.5 times higher per million preterm births than in industrialized countries. This suggests that coverage of high quality programmes needs to increase together with improvement in the quality of care of preterm births.

#### ROP as a cause of blindness in children in the Altai region \_\_\_\_\_ Dr Vladimir Lebedev

Dr Lebedev presented data on the number and causes of blindness amongst children presenting to the eye Department in Altai Regional Hospital, which is a tertiary referral hospital. The number of children presenting blind from ROP has increased over the last few years and is now the second commonest cause. Most children were not cared for in neonatal units in Barnaul but were referred from neighbouring regions.

#### Clinical features and classification of ROP. Dr Graham Quinn

Dr Quinn outlined the history of the classification of ROP over the years, and went through the current classification (The international Classification of ROP) which was revised a few years ago. The revised version kept the same broad classification, making amendments: 1. Aggressive Posterior ROP (AP-ROP) was described; 2. Clarity was given on how to identify whether disease was in Zone 1; and 3. A category of "pre-plus" was added when there are changes in retinal blood vessels (i.e. tortuosity of arterioles and dilation of venules) but the changes are not severe enough to be denoted as plus disease.

### Neonatal practices related to ROP. Prof Brian Darlow

Professor Darlow explained how there is not one single risk factor for ROP as the overall quality of care is important. The rates and severity of ROP can, therefore, be said to be an indicator of the level of care received. The evidence of the effectiveness of a range of interventions which improve the outcomes of preterm birth were presented, highlighting their impact on rates of ROP. This included antenatal steroids, gentle care immediately after birth by avoiding ventilation and oxygen as far as possible, delayed cord clamping and control temperature. Other important aspects of care include nutrition (focusing on human breast milk), and pain and infection control. Nurses play a vital role in promoting survival as reducing the risk of ROP, which requires well trained staff, high nurse: baby ratios and team work.

There has recently been considerable controversy over optimal oxygen saturation targets for preterm infants, and several multi-centre randomized trials have been undertaken in Canada/Europe/South America, the UK, USA and Australia. The evidence emerging from these trials of infants <28 weeks gestational age is that the lower target saturation range (85-89%) is associated with a lower risk of ROP but a higher risk of mortality than the higher target (91-95%). The current recommendations are to target oxygen saturations in the range 90 to 94%. Extra vigilance is needed to avoid saturations above 95% in very preterm infants on supplementary oxygen if a further epidemic of ROP is to be avoided.

Data on rates of treatment for ROP from the Vermont-Oxford network in 2003 showed that 11.1% of all infants <1500gs were treated for ROP: the rate in the 25% best performing units was 4.4%. By 2012 the overall treatment rate had fallen to 6.4%, and no infants were treated in the 25% best performing units. The findings highlighted the value of neonatal networks, and shows that rates of ROP can be minimized by excellent neonatal care.

### ROP programmes in neonatal units at Saint-Petersburg, Dr Elvira Saidasheva

Dr Elvira Saidasheva explained that neonatal care is of very high quality in St Petersburg, with a considerable number of infants with gestational age <27 weeks surviving. Babies are examined the unit under topical anaesthesia by Dr Saidasheva.

### Follow up of premature babies-neonatologists perspective, Professor Brian Darlow

Infants with very low birth weights (VLBW) are at increased risk of other ocular complications of preterm birth including high myopia, optic atrophy, strabismus and amblyopia. Neuro-developmental conditions also occur.

Neurosensory impairments – cerebral palsy:	10%
Behavioural problems, cognitive delay and educational underachievement:	40%
White matter abnormalities on brain MRI at term equivalent predict later problems:	49%

All infants with BW <1500g admitted to a NICU in New Zealand in 1986 were followed up. 82% survived. At the age of 7-8 years 5% had severe disability (unable to walk due to cerebral palsy; blind; IQ >3 standard deviations below the mean); 5% had moderate disability and 15% were mildly disabled (i.e. mild cerebral palsy; IQ 1-2SD below the mean). At school age, children born with VLBW are 2-3 times more likely to have behavioural problems, cognitive impairment and below average performance than children born at term. Many children have more than one morbidity. Subtle visual morbidity such as reduced stereopsis, poor convergence and visual perception problems are also 2-3 times more common.

Assessment of quality of life of infants recruited to the CRYO-ROP study at 10 years, showed that parents of children who were blind often gave their children very low QoL scores, with

some parents recording scores equivalent to “worse than being dead”.

#### Monitoring for the functional outcomes in children with ROP. Ludmila Kogoleva

Dr Ludmilla Kogoleva presented the structural and functional outcomes of children born preterm who had visual loss from ROP and optic atrophy.

#### Poster session:

As it was not possible for participants to make and bring posters, apart from one, three presentations were made.

#### Detecting serious ROP Graham Quinn

Dr Quinn outlined the advantages and disadvantages of telemedicine to screen for ROP, with the major advantage being that a camera based system allows screening to take place at a time convenient to the neonatology team (e.g. when the infant is more stable; when the child returns for follow up after discharge) in remote locations where there may be few ophthalmologists. It is essential that any telemedicine approach has very high sensitivity (i.e. no true cases are missed). Another advantage is if the images are taken and interpreted by a trained technician or physician, as this frees up the time of ophthalmologists. The feasibility, validity, cost effectiveness and safety of a multi-centre telemedicine project led by Dr Quinn which involved 13 centres across the USA and Canada will report the findings very soon. In this project images were taken by trained technicians, and technicians also interpreted the images at a reading centre.

#### Treatment of ROP and Laser vs anti-VEGF, Graham Quinn

Dr Quinn provided data supporting the current standard of treatment, i.e. peripheral laser photocoagulation of the avascular retina, and compared this to the use of intravitreal anti-VEGF drugs (usually Avastin or Lucentis) as a treatment for severe ROP. In contrast to the more than 25 years of data supporting a benefit to visual function and ocular structure after peripheral retinal ablation, there are sparse data supporting use of anti-VEGF drugs including so far case reports and series and a single randomized, non-blinded clinical trial (BEAT ROP) reported in 2011. Though a promising treatment, Dr Quinn urged caution using such treatment until more is known about the long and short term ocular and systemic effects.

### **MASTER CLASSES**

Master classes were held by Elvira Saidasheva, Ludmila Kogoleva, and a neonatologists on using the RetCam to examine infants for ROP, laser treatment and the role of nurses and pediatricians during examination and treatment.

#### **Day 2**

Participants: Approximately 45 participants attended the second day, 12 of whom were nurses who joined the workshop.

## **GROUP WORK AND SEMINARS**

### **Activity 1**

In sub-specialty groups, individuals were asked to identify the three main challenges of relevance to ROP they face in their work. The ophthalmologists discussed using a standard data collection form to document their findings, and the possibility of an online system of data collection. The neonatologists discussed their role in training and building the capacity of nurses and how this might be improved, and the nurses attended a session on how they can improve neonatal care to reduce the risk of ROP

### **Activity 2**

In the next three sessions regional groups were formed, with ophthalmologists, neonatologists and nurses from the same location in each group. The groups attended three seminars in turn, which were facilitated by the international facilitators:

- |  |               |
|--|---------------|
| 1. Improving communication             | Brian Darlow  |
| 2. Expanding ROP programmes            | Graham Quinn  |
| 3. Improving quality of ROP programmes | Clare Gilbert |

The topics were varied depending on the composition of the group, and other topics were discussed, including visual agnosia, and the role of telemedicine for detecting ROP.

### **Conclusions**

Intensive neonatal care has expanded and improved in Russia over the last decade, and 32 new intensive care units are planned. All the new units will have equipment for detecting and treating ROP (i.e., RetCams and lasers).

The quality of new born care has improved, reflected in improving survival rates. Much of the capacity building in neonatal care has taken place in Moscow or St Petersburg. There are international collaborations between neonatologists in St Petersburg and Sweden, with increased participation in international conferences and meetings. Improvements in neonatal care are being spread across the country, with many good practices such as swaddling, kangaroo care, and feeding using the mother's breast milk (but not always through breast feeding per se).

Some units lack blenders, and not all infants can have continuous oxygen monitoring.

As in many countries, there is a shortage of neonatal nurses (all are qualified nurses) and 'international' standards of nurse to baby ratios cannot always be met. Although there is in-service training of nurses by neonatologists, there is a lack of courses specifically designed for the nursing community. In Russia nurses are not permitted to talk to parents about their baby's diagnosis, which limits their capacity to counsel parents.

Some preterm babies remain in smaller maternity hospitals for up to 7 days before being transported to a higher level NICU. There are helicopters to transport sick babies between units where distances are large.

Guidelines for neonatal care were developed several years ago, and guidelines for the detection and treatment of ROP were developed in 2011. The screening criteria are wide (<2000gs or <35 weeks), which is a good approach as it is unlikely that infant with severe ROP are being missed. However, the wide criteria are increasing the workload on ophthalmologists who undertake the ROP examinations.

Programmes for the detection and treatment of ROP are well established in the Altai region but providing services to some remote areas is challenging. To increase coverage of programmes there is a mobile unit with a RetCam. Most intensive care units have at least one ophthalmologist trained in detecting and treating ROP, and many have RetCams and lasers. ROP services in Barnaul are well organized, with good systems for identifying babies to be examined. However, it was acknowledged that staff could be more proactive in contacting mothers who do not bring their infants back for examination after discharge from the unit, and the data collected are not being compiled for monitoring.

All preterm infants developing ROP are followed up in dedicated multidisciplinary clinics for one year, and in dedicated eye clinics thereafter until they are 18 years of age. Some of clinics for older children lack indirect ophthalmoscopes.

Many of the problems identified by participants were beyond their immediate control, such as low nursing levels which leads to long working hours with low pay; parents of preterm infants often have social problems (e.g. unemployment, alcohol abuse); distances are long, roads can be poor, and remote locations are inaccessible during the winter months.

There is a lack of services for infants with Stage 4 ROP in Siberia, and those needing treatment are referred to St Petersburg

### **Recommendations:**

1. Neonatologists and senior neonatal nurses to advocate for better nursing levels so they accord with 'international' norms
2. Neonatologists to review practices in relation to the timing of transport of preterm infants requiring higher levels of care, as experience from other countries shows that earlier transport (within 48 hours) is safe and gives better outcomes than deferred transport
3. Neonatologists and senior neonatal nurses to run regional training workshops for neonatal nurses
4. Ensure greater provision of oxygen saturation monitors so that all babies at risk of ROP can have continuous monitoring
5. Organize capacity building for nurses and other non-physician staff
6. Staff in the neonatal units to keep track of whether babies return for all their eye examinations and to be more proactive in contacting the parents of infants who do not return.
7. Ophthalmologists to develop and use a standardized system of data recording and collection (possibly leading to an online system). This will allow data to be monitored, identifying locations with above average rates of ROP, for example. Monitoring the birth weight and gestational age of infants being treated for ROP will allow decisions to be made whether the screening criteria can be modified (narrowed) to reduce the workload on staff and stress to babies.
8. Ophthalmologists to publish data on rates of ROP and the birth weight and gestational age of babies treated, to contribute to the international literature to increase the evidence for advocacy at the global level.

9. All clinics which follow up children with ROP to be provided with indirect ophthalmoscopes so that late complications (e.g. retinal holes; retinal detachment) can be detected early.
10. Internet site to be developed so that parents can readily obtain information about prematurity and ROP
11. Neonatologists and ophthalmologist to start considering how programmes might respond when high quality, lower cost retinal cameras suitable for ROP become available.
12. Future workshops to include obstetricians to increase awareness of their role in preventing ROP in babies born preterm (i.e. antenatal steroid use; resuscitation starting with room air; avoiding early ventilation; delayed cord clamping)
13. Develop a surgical centre for advanced ROP in eastern Russia

## Groupwork Sessions on day 2:

Group 1 consisted of ophthalmologists involved with follow up of premies:

Topic: Extending reach of good ROP programs

Within the NICU unit

- 1 Fewer units with better equipment preferred for inpatient care
- 2 Development of care teams for long term relationship with family and the children
- 3 Include obstetrics into the conversation

Nurses in labor and delivery who follow-up til 7 days – 1 nurse for 8 premies babies (nurses are on for 24 hours)

Follow-up pediatric ophth clinics

- 1 Have one trained person who is responsible for follow til age 16 years
- 2 Lack of ancillary staff so physician does all testing and procedures. This is likely due to poor pay for these people. Sacrifices quality of care
- 3 Equipment seriously lacking in the follow up
- 4 Poor method for referral after discharge and poor organization of support for the families
- 5 Need vitreoretinal surgeon locally

Group 2: consisted of 1 neurologist, 3 ophthalmologists, 2 neonatal nurses, 1 neonatologist, 2 nurses for ophthalmology department, all representing 2 regions

Topic: How might telemedicine be useful in extending ROP coverage?

- 1) There are NICUs with at risk babies who are not currently being examined.
- 2) 5 years from now:
  - a. Group A. perhaps better equipment will be available, but there will likely be more babies with serious ROP and they will have to be taken care of. Emphasis should be on the kindergarten level for providing information and equipment.
  - b. Group B: telemedicine equipment should have a lower priority than providing improved neonatal care. Don't need a camera in each clinic, but need to train more ophthalmologists to recognize severe disease and treat it.

Group 3 consisted of 3 ophth, 2 NICU nurses, 1 neonatologist

- 1) RetCam currently being used by ophthalmologist and images sent out for consultation as needed
- 2) There are NICUs in these areas that are not covered and there are no ROP programs. Considering outreach to these NICUs, but worried about damaging machine so would think that indirect ophthalmoscopy would be preferred.
- 3) In Samara, outreach activities are well organized with a clinic on wheels or "railways of health." Go for a week with physicians and equipment for adult ophthalmological problems.

## **Appendix 1 Timetable ROP workshop, Barnaul**

### **Day 1**

#### **SESSION 1**

8.00	Registration	
8.30	Welcome speech	
9.00	Aims and objectives of the Workshop Katargina	Professor Ludmila
9.10	ROP as a cause of blindness in children globally	Clare Gilbert
9.30	ROP as a cause of blindness in children in the Altai region Lebedev	Vladimir
9.50	Clinical features and classification of ROP	Graham Quinn

10.10-10.30 BREAK

#### **SESSION 2**

10.30	Neonatal practices related to ROP	Prof Brian Darlow
11.00	ROP programmes in neonatal units at Saint-Petersburg	Elvira Saidasheva
11.30	Follow up of premature babies-neonatologists perspective	Brian Darlow
12.00	Monitoring for the functional outcomes in children with ROP	Ludmila Kogoleva
12.20	Identification of challenges - written task	Participants

12.30 LUNCH

#### **SESSION 3**

13.30	Poster session * (Ophthalmologists/Neonatologists/Nurses from each NICU)	
15.00	Detecting serious ROP	Graham Quinn
15.15	Treatment of ROP and Laser vs anti-VEGF	Graham Quinn
15.45	Master-class. Diagnostics of ROP using RetCam imaging	Elvira Saidasheva
16.15	Master-class. Laser treatment of ROP	Ludmila Kogoleva
16.45	Role of nurses and pediatricians during eye exam and treatment	Neonathologists

## Day 2

### SESSION 4

In speciality groups For discussion: prioritise main challenges and possible solutions

Ophthalmologists  
Faculty: Graham Quinn

- ⌚1 Write down 3 problems in their work in relation to ROP
- 2 Standard data collection for ROP
- 3 Online data entry system
- 4 Need for training in ROP diagnosis and treatment

Neonatology /  
neurologists  
Faculty: Clare Gilbert

- 5 Write down 3 problems in their work in relation to ROP
- 6 What are they currently doing to improve the knowledge and skills of nurses
- 7 How might they improve this / team building?

Nurses  
Faculty: Brian Darlow

- 8 Write down 3 problems in their work in relation to ROP
- 1 Improving neonatal care

10:15 Feedback in groups

10:30 Plenary feedback by rapporteurs

### Break

### SESSION 5

11:30 Regional groups x3

A Improving communication.  
Darlow

Brian

B Expanding ROP programmes  
Quinn

Graham

C Improving quality of ROP programmes Clare Gilbert

### Lunch break

### SESSION 6

1:30 Regional groups x3

B Improving communication  
C Expanding ROP programmes  
A Improving quality of ROP programmes

2:30 Regional groups x3

C Improving communication  
A Expanding ROP programmes  
B Improving quality of ROP programmes

3:30 **Tea break**

### SESSION 7

4:00 Feedback from groups by facilitators

5:00 **Conclusions and recommendations**