



## Annual Report for Shreveport Sees Russia (SSR) 2013



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## Shreveport Sees Russia: Supporting the prevention and treatment of childhood blindness in Russia and Eastern Europe

### Executive Summary

With the support of Shreveport Sees Russia IAPB has made significant steps towards improving the prevention and treatment of ROP in Russia and Eastern Europe. IAPB sponsored a national ROP workshop in Bulgaria, bringing together 67 paediatric ophthalmologists, neonatologists and nurses to review and update their national ROP guidelines. IAPB continues to build the important alliances with key senior paediatric professionals in Russia and through this are able to support their national ROP programme through workshops and training opportunities. As a result of this partnership and the advice of SSRs ROP advisors Russia held their first ROP conference. Other initiatives include a month long VR observership for Dr. Denisova from Helmholtz, Moscow, in the US and training for ophthalmologists from Russia and the Ukraine at the LV Prasad Institute in Hyderabad.

Exciting steps have been made in South East Europe where Professor Clare Gilbert ran a ROP course at the regional Black Sea Ophthalmologists conference in Tbilisi. From this a regional ROP group has been established and they are already planning their first regional ROP workshop in 2014.

### ROP Blindness in Russia and Eastern Europe

Retinopathy of prematurity (ROP) is a potentially avoidable cause of irreversible, and usually total blindness in infants who are born premature. Fig. 1 shows the high risk of childhood blindness from ROP in Eastern Europe and Russia. However much of this can be avoided if countries develop neonatal care facilities with trained paediatric ophthalmologists, neonatologists, neonatal nurses providing a ROP screening and treatment programme.

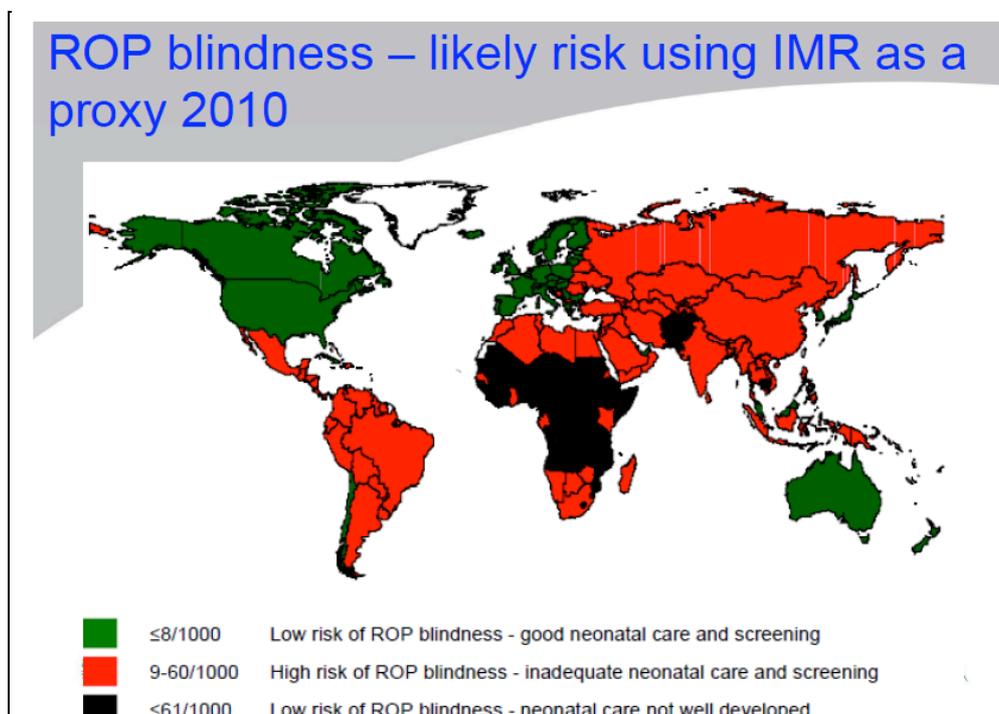


Fig. 1 – Global risk levels of ROP, 2010 (Clare Gilbert)

Blindness from ROP can be controlled through:

- Excellent neonatal care in Neonatal Intensive Care Units (NICU's). Trained neonatologists and nurses monitoring the key risk factors. Most importantly to monitor oxygen saturation levels for all infants who receive additional oxygen.
- Detection and treatment of infants who develop severe stages of ROP. Screening for all at risk infants to detect treatable stages of the disease, followed by laser treatment.

### **Health systems in Eastern Europe**

In Eastern Europe the problem is complex and multidimensional with all parts of the health system needing strengthening. It is characterised by:

- Poor leadership and governance – the lack of strategic leaders able to advocate with Ministry of Health (MoH) for improved resources and for ROP policies and guidelines.
- Neonatal and ophthalmology teams working in isolation - need to unify and work together to effective screening and care for infants at risk
- Research and data – very little information on the extent of the problem. Poor HMIS to track the problem.
- Equipment – many neonatal units do not have the basic package of essential equipment to screen and treat ROP effectively.
- Human Resources –under resourced in terms of numbers, poor skills, motivation, guidance and opportunities for neonatal and ophthalmological staff
- Service delivery – no guidelines and policies resulting in poor neonatal care and associated ROP which could have been prevented.
- Finance – lack of financial resources allocated to increase staffing levels and provide vital equipment

IAPB has the benefit of learning from the International Centre for Eye Health's experience in Latin America where a regional ROP programme has recently been evaluated showing that the model of training teams, advocacy at national level and developing country specific ROP guidelines have gone a long way in preventing ROP across the region. This is a model that we plan to use in Eastern Europe and Russia, but adapting it to local needs.

### **IAPB's strategy:**

#### **Aim of the IAPB ROP Europe programme:**

To support the Ministries of Health, specifically the neonatal and paediatric ophthalmic teams, to develop and implement efficient, effective and equitable national ROP programmes. This is done through a combination of training opportunities, exposure to international seminars and events and supporting national and regional ROP workshops. Strategically the programme aims to, through exposing influential leaders in ROP to the latest developments, create the demand for training and facilitation support to develop national ROP policies and guidelines. The key to success is the development of strong relationships with leaders working on and responsible for ROP within the Ministries of Health.

SSR has provided \$123,283 over 3 years (2011 – 2013). In 2013 \$ 61,500 was received and the expenditure was \$ 40,205 these funds have been used to support the following activities:

## **2013 Programme activities:**

### **National ROP workshops: Bulgaria**

In 2013 SSR sponsored a national ROP workshop in Sofia, Bulgaria May 10<sup>th</sup> – 11<sup>th</sup>. This was a follow up workshop to the 2009 workshop held in Varna, Bulgaria. This was a critical workshop as it was the first to bring together both East and Western Bulgarian ophthalmologists to review and update the guidelines produced in 2009. The workshop was well attended with 30 ophthalmologists, 30 neonatologists and 7 neonatal nurses. The workshop also had excellent coverage on the national news. A team from the U.K. delivered the workshop and facilitated group sessions; the team included an ophthalmologist, neonatologist and a neonatal nurse. Their current ROP guidelines were discussed as well as the UK nursing guidelines, copies of which were given to participants. The UK team also had the opportunity to visit a local NICU to observe the screening and treatment of infants.

### **Outcomes:**

It was agreed that a multidisciplinary approach was needed to manage ROP in Bulgaria and a national ROP Committee to be established to take this, and other recommendations, forward. Names for a national ROP committee were listed and will be pursued by Dr Chernodrinska who has links to senior Ministry of Health decision makers.

Participants agreed that a standardised approach to collecting data from every unit was required and the need to have a national database.

The UK team prepared a list of recommendations for the host which have been shared, many of which depend on local advocacy with the Ministry of Health to make the necessary changes but there are some recommendations which IAPB may be able to support.



*ROP Workshop – Sofia, Bulgaria*

- **National ROP Conference, Helmholtz, Moscow, Russia**

Support from SSR has enabled IAPB to build on our contacts in Russia, primarily with Professor Ludmila Katargina of the Helmholtz Institute. Professor Ludmila is a very senior paediatric ophthalmologist who advises the Ministry of Health on paediatric ophthalmology. SSR has supported Professor Ludmila through sponsorship of influential international speakers who are global leaders in ROP programming to attend key Russian conferences. They are Professor Clare Gilbert, Professor Brian Darlow (a neonatologist) and Graham Quinn. They were invited to present at the annual All Russia Ophthalmological Forum (AROF) conference in 2011 and 2012, following which there was a request for the faculty to present at Russia's first International Scientific Conference on ROP 2013 April 11<sup>th</sup> -12<sup>th</sup>. This was the first of its kind and a significant step forward; it also provides an exciting opportunity for our team to work and support Professor Ludmila as she develops the Russian ROP programme.

The team (Quinn, Gilbert and Darlow) all made presentations at the conference and then there were a series of questions and discussions, a positive move towards a more interactive approach to meetings which is what the team have been advocating for.



*Prof Darlow visiting a NICU, Moscow*

**Outcomes:**

National Guidelines are being established, including determining which premature babies should be examined for ROP.

Request for an international observership in VR surgery – now completed.

Identification of the need for training in ROP programme management and treatment to run alongside the introduction of new lasers to all Provinces – now completed

The need to pilot a Provincial ROP programme and to start by having a Provincial level ROP workshop – possibly Altai Province in 2014. Planning underway.



*International faculty – Professor Gilbert, Darlow and Quinn with Professor Ludmila at the ROP Conference, Moscow, Russia*

- **ROP Course and Regional Meeting: Black Sea Ophthalmological Society, Tbilisi, Georgia**

In order to develop more contacts in Eastern Europe and to assess needs with a view to providing support to national ROP programmes IAPB Europe arranged for Professor Clare Gilbert to give a course on ROP at the annual Black Sea Ophthalmological Society congress in Tbilisi, Georgia, May 24<sup>th</sup> – 26<sup>th</sup>. IAPB also provided travel grants for ROP ophthalmologists nominated by their national ophthalmological society to attend the conference, Clare's ROP course, and to make a presentation of their national data on ROP.

Following the course a meeting was held with the sponsored country representatives to discuss their data, common challenges and opportunities to work as a group to strengthen national programmes. Also in the meeting ideas were gathered on inter regional support with some countries well placed to support some of their neighbours.

**Outcomes:**

The outcome of this meeting was twofold, firstly a set of data and information on the status of the national ROP programmes across the region. These data are being gathered by IAPB Europe. It also highlighted the fact that there had been no surveys and there was very little data on the prevalence of ROP.

Secondly a commitment to holding a regional ROP workshop in 2014 bringing together neonatologists with the paediatric ophthalmologists. Since the meeting it has been agreed that the Filtov Institute in Odessa, Ukraine will host it. This workshop will be the first to bring together all those responsible for the care of premature babies – this was recognised as being critical to the success of any initiative. The Odessa workshop will also be used to build up the confidence and skills of new faculty with the aim of developing a cadre of workshop facilitators from the region.

- **Training/Observerships – VR Observership, Michigan, USA**

At Professor Ludmila's request Graham Quinn secured an observership for Dr Denisova, the lead VR surgeon at Helmholtz who operates on severe ROP cases that require VR surgery. She spent one month, 19<sup>th</sup> November – 19<sup>th</sup> December, at the Associate Retinal Consultants practice in the USA. [http://www.associatedretinalconsultants.com/visiting\\_scholars.htm](http://www.associatedretinalconsultants.com/visiting_scholars.htm) Initial feedback from Dr Denisova indicates that the training is excellent and will enable her to not only improve her clinical skills, but also some of the management practices. She also intends to roll out her learning and new skills through training others.

**Outcomes:**

Dr Denisova's feedback was:

*'I have learned many pieces of new and useful information about the diagnosis and treatment of different pediatric retinal diseases, attended 40 operations and 26 examinations of children under anaesthesia, observed children and adults in the clinic with Dr. M. Trese, Dr. A. Capone and Dr. G. Williams. Together with Dr M. Trese we have prepared an article named Telemedicine with smart software for retinopathy of prematurity screening for the journal - Russian Pediatric Ophthalmology. I hope that this article will be helpful for Russian doctors and will contribute to the improvement of the diagnosis and treatment of ROP in Russia. Dr. M. Trese presented me a CD disk with many articles about ROP and pediatric retinal diseases. I will obviously share the acquired knowledge with my colleagues and apply new skills in Russia!'*

Actions after the observership:

*I shared the acquired knowledge with my colleagues. We are planning to apply telemedicine for retinopathy of prematurity screening in Russia more widely. We are going to speak with our biochemical laboratory about preparation of autologous plasmin that is necessary for creating posterior vitreous detachment in pediatric vitreoretinal surgery. We are also planning to improve surgical techniques in advanced stages of retinopathy of prematurity and other pediatric vitreoretinal disorders. We are also going to do FAG in babies with retinopathy of prematurity and other vitreoretinal pathology under anesthesia using RetCam. We are aimed at conducting genetic investigations in pediatric vitreoretinal diseases in Russia in order to apply gene therapy in the future.*



### **Training/Observerships: ROP Management Training – LV Prasad Eye Hospital, Hyderabad, India**

During the ROP conference in Moscow in April 2012 Professor Ludmila was able to announce that the Ministry of Health, being increasingly aware of the ongoing and potentially increasing problem of blindness due to ROP, had agreed to supply each of the 49 regions of the country with a wide-field digital imaging system for detecting babies with severe disease, a laser for treatment and an indirect ophthalmoscope. It was clear during discussions that some training would be required to ensure that the new equipment would be used effectively, safely and also be embedded into a well organised ROP programme. Professor Gilbert was able to arrange for two lead paediatric ophthalmologists, one from Russia and one from Ukraine, to be trained alongside the internationally recognised expert Dr Subhadra at LVPEI, Hyderabad, India. The aim being that they would then have the skills to enable them to train up others in advance of the new equipment being received. This training provided a combination of clinical and managerial/organisational skills over the two week period, 30<sup>th</sup> September – 12<sup>th</sup> October.

LVPEI was identified as the perfect place due to their highly efficient ROP programme and also the fact that they see a large number of children with ROP as it serves a very large and densely populated area. This training was arranged to provide the skills to the lead ophthalmologist from Moscow, who will, on her return, be able to train up others in the regional units. The main purpose of this training was to prepare the unit staff in each region so that they would be ready for the arrival of the new lasers and other equipment. This then would lay the foundations for effective programmes in each region with both the skills and

equipment in place. The true strength of this is that IAPB has been able to respond directly to the needs expressed by the partner, Helmholtz, not only does this ensure that the training is what is required and wanted but also will help ensure that the trainees will be provided opportunities to utilise and pass on their new skills on their return.



*ROP training – LVPEI, Hyderabad, India*



*ROP training – LVPEI, Hyderabad, India*

**Outcomes:**

Feedback from the doctors: *'....and we did see all the levels of ophthalmology care for premature born babies starting from neonatal hospitals and screening there, laser treatment and vitreoretinal surgery for different stages. We also got a chance to see the follow up and what is not less important psychological care for the kids with vision problems. Along with this we had a chance to talk and to see the work of brilliant surgeons dealing with corneal surgery, strabismus..... As we do provide care for all the stages of ROP in Ukraine it has been very important to see some different approach for different techniques, compare the results and to exchange our knowledge. Dr. Subhadra Jalali is an admirable woman, brilliant specialist and a person with a BIG heart. We've spent quite a bit of time not just working with patients but also discussing problems of ROP. She spoke about how they established the whole thing with ROP starting from telling all the related specialists about the importance of the problem, teaching trainees and make them want to learn, organizing anaesthesiology care. We basically face same problems in Ukraine and it was nice to exchange our experience.'*

*'We are very grateful for the possibility to study in LV PEI in Hyderabad. Dr Subhadra is a miracle woman, who firstly, is an excellent vitreoretinal surgeon. Perhaps, she is one of the best expert in vitreoretinal surgery in ROP, as in Russia the famous vitreoretinal surgeon Oleg Diskalenko from St Petersburg.... Lectures of Dr Subhadra were dedicated not only the treating of ROP, so to the different organizational problems, psychological approaches to the parents, blind children.*

*I was very interested in the system of organization the help to children with ROP in India, methods of education of screening and treatment of ROP..... The experience, I got during the education. I will apply at organization of education programmes in diagnostics and treatment of ROP in Russia.'*



*ROP training – LVPEI, Hyderabad, India*

As illustrated so well in the feedback both doctors are very keen to put their learning into practice on their return. Dr Astasheva specifically mentioned that she plans to apply what she learnt to organise an education programme in the diagnostics and treatment of ROP in Russia. We will request a follow up report six months after their return to post. We also hope to get first hand feedback from Professor Ludmila at the next Russian ROP workshop.

- **2014 Plans**

**ROP Workshops:** Building on the work to date there are already several workshops planned and in the process of finalising dates, faculty etc. During these workshops training needs and other support opportunities will be identified.

May 2014: Regional Black Sea ROP Workshop : Odessa, Ukraine

June 2014: Provincial ROP Workshop: Altai Province, Siberia, Russia

September 2014: National ROP Workshop: Bucarest, Romania

**Capacity Building:** We hope to identify and mentor regional ophthalmologists and neonatologists who can become faculty for the region. We also hope to identify a regional institute which can be supported to provide faculty and training for the region in the future. The mechanism for doing this is informal and through networking and observation during the workshops.

**ROP Data:** Discussions are already underway for Professor Gilbert to train up a colleague in Hungary to conduct a blind school survey and also to roll out the training to mentor others such that other regional surveys can be conducted.

There will be an opportunity for 1 (possibly 2) European representatives to be trained up to become a RAAB Master trainer. This will provide them the skills they need to lead RAAB surveys in the region.

**Resources:** We have approval to translate the UK parent information leaflets from the UK ROP guidelines into 14 European languages.

We also plan to develop an essential list for ROP which will be published under the IAPB Standard list. <http://www.iapb.org/initiatives/standard-list> Professor Gilbert is providing her technical expertise to this.