



September 10th 2014

Alan and Rishia Richards

Shreveport Sees Russia

Dear Alan and Rishia,

I hope this finds you both very well. It is almost two years since I last wrote to express our heartfelt thanks for the impact your support has produced towards the elimination of avoidable childhood blindness, through Retinopathy of Prematurity in Russia and Eastern Europe. As before I would be very grateful if you would especially thank **Mr. James K Elrod**, who I am very aware, is a very significant individual supporter of our work. I, and all at IAPB, are immensely grateful for his wonderful commitment.

When I wrote two years ago I reported on our early work in Russia and of building contacts with key people such as Professor Ludmila Katargina from the Helmholtz Research Institute for Eye Diseases. A significant step towards ROP treatment had just materialised with the decision by the Ministry of Health to purchase a wide-field digital imaging system, a laser and an indirect ophthalmoscope for each of the 49 provinces of the country. We had also begun to sponsor paediatric ophthalmologists to attend Congresses where they were gaining information, learning from others and networking. Our plans for 2013 and 2014 were to continue these initiatives and to expand our work into South East Europe, especially in Bulgaria and Romania.

So two years on, what have we done and what have we achieved?

I think we can show significant progress and successes – though the political situation, at least in recent months has been very difficult. It's a fair bet that anyone reading news from Russia or the Ukraine recently won't have been seeing coverage on health systems or childhood blindness! Specifically, the unfolding crisis in the Ukraine forced us to reschedule the regional workshop for the Black Sea States away from Odessa to Budapest.



The workshop was extremely effective, bringing together a total 53 ophthalmologists, neonatologists and neonatal nurses from six countries in the region, and as Neonatal Intensive Care units (NICU's) teams they were able to work together to improve their own national plans and guidelines.

To give you a fuller picture of our programme and the value of your support, I have asked our principal specialists to each write short personal reports of their contribution towards our overall objective of improved national programmes for screening, prevention and treatment for ROP. I am appending these personal responses to my letter.

We are very fortunate to be able to call on the services of leading global specialists in the field of childhood blindness. Professor Clare Gilbert describes her work in Russia, starting with a short talk in 2009 to the position now where national guidelines are in place and she has a strong working relationship with key national advisers for children's health. Professor Graham Quinn also describes his involvement in Russia and highlights the importance of the Russian attendance at the Third International ROP Congress in Shanghai as a turning point in their views towards improved care for premature children. This was only made possible through the support of Shreveport Sees Russia. Professor Brian Darlow writes of his involvement with neonatologists and neonatal nurses and the improvements in the equipment and protocols, however a remaining concern is the shortage of trained nurses and this remains an area for continuing advocacy.

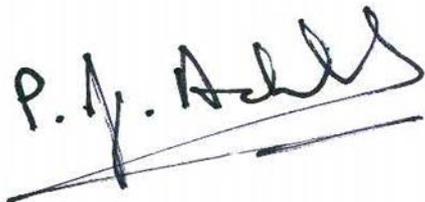
Finally I am very pleased to include feedback from Dr Kateryna Fedchuk, a paediatric ophthalmologist working in Kiev, where she and one other colleague screen and treat 1,000 premature births each year. Dr Fedchuk had earlier received a bursary through Shreveport Sees Russia to attend the 2nd World Congress of Paediatric Ophthalmology and Strabismus in Milan, following this we were able to support her to train at the specialist LV Prasad Eye Institute in Hyderabad, India. The great range of experience in ROP treatment Dr Fedchuk gained from her study has allowed her to improve the protocols in her own hospital and also to pass on this training to paediatric ophthalmologists from across the Ukraine. This is helping bring about very real improvements in childhood eye care in the country, and working towards the elimination of avoidable blindness through ROP. The credit for this rests with the direct support from Shreveport Sees Russia.

Our overarching strategy to eliminate avoidable blindness through ROP is built on our previous experiences in Latin America, where we have seen dramatic improvements in childhood blindness programmes. Strong national plans and resources are necessary at the primary stage, to prevent ROP from occurring in the first place, at the secondary level to screen and prevent the consequence of the condition and at the tertiary level for interventions to restore visual function. Crucially, underlying these strategies ophthalmologists, neonatologists and nurses are trained, resourced and coordinate closely.

Moving ahead our immediate plans for the rest of this year are to support a national workshop in Bucharest to develop improved protocols, we will also sponsor two international speakers to attend the South Eastern European Ophthalmologist Society (SEEOS) meeting. The latter event will raise awareness and provide an introduction into Albania, Croatia, Bosnia-Herzegovina, Kosovo, Montenegro and Serbia. Finally we will promote better data on the numbers of children affected by ROP by training a group to carry out surveys amongst schools for the blind across the Black Sea region. Looking further ahead our strategy is ambitious. We will build on the SEEOS meeting to bring together a cross disciplinary NICU teams to examine and improve their own ROP programmes. We will also work to build capacity, we will support the Semmelweiss Institute in Budapest to become the first sub-regional 'hub' for training and observerships, we will also support inter-country mentoring arrangements, the first being a team from Moldova who will be travelling to Turkey to learn from their national programme. Through these measures we believe we will be able to produce the most effective and sustainable improvements to childhood blindness programmes in the area.

I hope this demonstrates the tremendous impact your support is already having in the region, and the scope of the potential open to us. Once again I would like to express my sincere thanks for the importance that your efforts are delivering towards eliminating avoidable childhood blindness.

With very best wishes,

A handwritten signature in black ink, appearing to read "P. J. Ackland", written over a horizontal line.

Peter Ackland

Chief Executive

International Agency for the Prevention of Blindness

A Personal Reflection on the value of ROP training at the LV Prasad Eye Institute – Dr. Katernya Fedchuk.

Dr Fedchuk works at the Ukrainian Medical Center of Pediatric Ophthalmology and Eye Microsurgery which is a structural part of National Pediatric Hospital "Ohmatdyt" in Kyiv, Ukraine. Although the Center was only established 9 years ago the staff are young and keep in time with modern technologies so as to respond to needs of the National Hospital as the most difficult pathologies are directed here. Dr. Fedchuk works as a pediatric ophthalmologist and her responsibility is premature born babies. Due to achievements of neonatology more and more patients annually face the problem of ROP. Dr. Fedchuk is screening babies in the Neonatal Center on Tuesdays and Fridays - 15 to 45 babies per check-up (and other days if needed) and on Wednesdays and Fridays - babies after discharge from local NICU's and also from all over Ukraine if required.

Up to 1,000 premature newborns are followed in the Center annually. It is only Dr Fedchuk and one other ophthalmologist who are doing all the screening and treatment at the Centre; this is clearly an untenable situation in the long term and one of the main constraints to delivering an efficient ROP programme as it depends on the motivation and volunteering of the two ophthalmologists.

All the parents despite their social or economic condition should be able to see a local ophthalmologist who has appropriate equipment (indirect ophthalmoscope) free of charge. This is a good thing about medical service organization in Ukraine, meaning that all the regions (24+Crimea) have at least one professional who should know ROP brilliantly and means that families will not have to travel too far for screening. Nevertheless errors occur due to the reasons which should not be difficult to fix. In some cases either neonatologist or ophthalmologist doesn't explain thoroughly the importance of the problem to the parents, in another the ROP stage isn't interpreted correctly. Thankfully the quantity of such instances goes to minimum each year as the Center gets more pre- and threshold cases and less stage 5 ROP. The number of late stage 5 vitrectomies went down from 74 in 2011 to 27 in 2013.



Dr Fedchuk was selected by Alan Richards as being a perfect candidate to attend the ROP training with Dr Subhadra at LVPEI in India. The programme is ideal in that it sees a high number of referrals and allows the visiting ophthalmologists to see many, often, complicated cases. The training programme covers all aspects of a ROP programme, including the information management, research and data collection, screening and treatment, parental education and support, and training. It is an intensive programme six days a week from 8 am to 6pm.

Dr Fedchuk is based at a leading ROP centre in Ukraine which provides services for much of the country, and acts as a training institute for others and so Dr Fedchuk is ideally placed to pass on her learning to other colleagues from across Ukraine. Twice each year pediatric ophthalmologists from all over Ukraine come to the Center by groups of 5 to 10 where they can see the way screening should be performed, they take part in exams, see the babies,

watch how laser and vitrectomies are performed. Going over RetCam pictures makes it possible to discuss controversial situations, what actually should be treated and what will only progress. Also every month to six weeks Dr. Fedchuk goes to local ophthalmological meetings to report about ROP and this gives her an opportunity to advocate for improved ROP services, particularly the importance of linking up with the neonatologists and nurses in the care of premature infants.

Some of the key lessons learnt from Dr Subhadra and her work at LVPEI were the importance of research and collection of data. Dr Fedchuk has plans to develop a unique form for data collection which she will pilot at the Centre with a view to rolling it out once it has been proved useful. She knows that in order to advocate for more resources from the Ministry of Health she will need to present a strong case.

In autumn there is a national Neonatology meeting to which Dr Fedchuk has been invited to lecture on ROP to both neonatologists and neonatal nurses on ROP. This is a wonderful opportunity to educate all and raise awareness on ROP and the importance of guidelines for screening for neonatologists and nurses.

To conclude the ROP service is working well in Ukraine and the quality of service improves each year, vision is saved in more than 200 newborns annually making them enjoy the beautiful world. But it should work perfectly; there should not be any “cases” where avoidable blindness due to ROP occurs. Dr Fedchuk plans to keep on talking about ROP, keep on teaching and discussing and passing on her knowledge. Most importantly is the need to collaborate with neonatal service since a successful ROP programme depends on quality neonatal care and an efficient referral system for screening. Ophthalmologists like Dr Fedchuk are trying to integrate their knowledge into NICU’s and each year and are heard more and more.



Dr Fedchuk has hopes to organize a national conference on ROP for ophthalmologists, neonatologists and neonatal care nurses to look at how best they can work together to improve the screening and treatment of ROP for Ukrainian babies. Most importantly Ukraine needs to find peace again to allow these and other programmer to develop for the people of Ukraine.

June 2014.

Professor Clare Gilbert
London School of Hygiene & Tropical
Medicine



I first went to Russia in 2009 to give a short talk on blindness in children due to retinopathy of prematurity (ROP) at a national meeting of ophthalmologists. The reason I was invited was because Professor Ludmilla Katargina had read some of my publications, which gave me great pleasure. I returned to Moscow again in April 2011, October 2012 and in April 2013. All the meetings were instigated by Professor Katargina who is head of the Helmholtz Research Institute in Moscow. She is also an adviser to the Ministry of Health for eye care in children and so is an extremely influential person.

The meeting in 2013 was for neonatologists and ophthalmologists from all the regions of Russia and there was a full day of presentations with some limited discussion. At each visit I had discussions with Professor Katargina and made suggestions concerning the next steps. At each visit I tried to impress upon her the importance of multidisciplinary workshops and so this was arranged for Barnaul in Siberia last month. This was an eye opening experience for all of us! It was clear that none of the Russian participants nor the organisers had ever been to a workshop - they did not know what to expect and seemed very uncomfortable with large periods of time in the programme without presentations. However, over the course of the two days participants realized that it was good for them to be able to discuss the problems and challenges they face and that they could learn from each other. At the end of the workshop Professor Katargina said she had enjoyed the workshop very much and in effect said “now I understand what workshops are all about”. At the end of the workshop it was quite a challenge delivering the conclusions and recommendations to ensure that what we said did not imply criticism. However, I have since had an email from the Professor Katargina thanking us, which was encouraging.



Many things have happened in Russia since I first went in 2009. I was amazed to hear in 2011 that 49 RetCams, which are used to take images of the retina (almost \$100,000 each), and 49 lasers had been purchased for the different regions. At one of the meetings a couple of years ago I gave a talk on the importance of national guidelines for ROP programs and last month we heard that a group of experts had been convened and national guidelines are now in place. I also gave presentations on the importance of policy, particularly in relation to preventing ROP through improving the care of preterm infants, and Professor Brian Darlow, a neonatologist from New Zealand, has given talks on the importance of the first “golden hour” after birth. Again, at the most recent workshop the Professor Katargina explained that the Ministry of Health plans to establish 52 more neonatal intensive care units across the country and that each will have equipment for diagnosing and treating the ROP.

It is obviously impossible for me to say how influential these presentations and meetings might have been, and all we may have done is given support and encouragement to Professor Katargina to enable her to advocate for what she had already planned. On the other hand, the Russians are extremely keen to develop services of the highest possible quality and as a result of input from the meetings and workshop they have been able to learn more quickly what is happening in other countries. Professor Katargina has also invited me to be a member of the editorial advisory board for the Russian Paediatric Ophthalmology journal, and I have agreed. Her long-term goal is that all the articles will be available in English, so attracting authors from other countries as well as providing a means for Russian ophthalmologists to learn what is happening in other countries.

We are all so very grateful for the support you have given to Shreveport Sees Russia which I do believe has been instrumental in bringing about the expansion and improvement of programs for the control of blindness due to ROP in Russian. We have all found the visits extremely interesting and it has been fascinating getting to know the country a bit from the inside.

August 2014.

Professor Graham Quinn
University of Pennsylvania



How Shreveport Sees Russia has supported the ROP programme in Eastern Europe.

My involvement with these projects dates back to 2011-12 when I presented short 30-minute talks at meetings in Moscow at the invitation of Professor Ludmila Kartagena. These meetings allowed me to meet ophthalmologists from many regions in Russia and to begin to understand the current ROP situation. It was clear that expertise was largely concentrated in Moscow and St Petersburg with limited access and expertise outside these areas. It was also apparent from various conversations and presentations that what ROP treatment was being given to many premature infants was suboptimal and did not follow established treatment regimens. For example, when images of treatment “failures” from laser photocoagulation were presented, it was clear that treatment had not been performed in the standard manner. The leaders, especially Prof Katargina, were supportive of efforts to improve care and welcomed international guests who could help move the ROP work in Russia forward.

In October 2012, we held a Third International ROP meeting in Shanghai which was attended by ophthalmologists, neonatologists, and neonatal nurses from many countries. Having Prof Katargina and several other Russian ophthalmologists were able to attend and present information on the current status in Russia. To my mind, this was turning point in which the Russians saw ways to improve care of the prematures in Russia and the support of SSR was key to this effort.

At a meeting in Moscow in 2013, Prof C Gilbert, Prof B Darlow and I participated in series of meetings in Moscow. It was clear at these meetings that good progress was being made in terms of ophthalmologic equipment and screening of babies at risk and this forward movement was very encouraging. In particular, support had been provided to Russian ophthalmologists to participate in training programs with international ROP experts in India and the US and these individuals had returned to share their expertise.

During the meetings in 2013, we emphasized with our Russian hosts the importance of group meetings in which the various stakeholders could interact in small group sessions as a way in which other regions with rapidly developing NICU systems were able to work together effectively. Prof Katargina raised the possibility of such a meeting in Russia then and suggested Bernal, Siberia for the meeting.

The First Russian ROP Workshop held in Bernal in June 2014 represented a big step forward. There is clearly greater interest in ROP now among the workshop participants. In

contrast to earlier meetings, neonatologists and neonatal nurses were strong and eager participants in the work of the meeting. The meeting provided a unique opportunity for interaction among ophthalmologists, neonatologists and nurses and the group gradually began to take advantage of the opportunity. Discussions concentrated on increasing ROP coverage in Russia, improving neonatal care, and decreasing ROP blindness - first step of this kind, but an essential one that requires continuing support and nurturing.

Other ROP efforts beyond Russia:

As part of our ROP blindness prevention effort, I was able to participate in meetings and visit NICUs in Poland and Hungary in June 2014. In Poland, I was able to visit several NICUs in Warsaw and Krakow and also attend the Annual Meeting of the Polish Ophthalmology Society to present on the use of anti-VEGF drugs in the treatment of acute phase ROP. The effort was facilitated by the participation of A Baumritter, MS, who is the project director for an ROP telemedicine project at Children's Hospital of Philadelphia and a native of Warsaw. She facilitated the meetings in Warsaw where we visited the NICU at the Children's Hospital and also a second large and very well run NICU in central Warsaw. Concerted efforts by ophthalmologists and neonatologists in Warsaw are moving ROP screening and treatment forward, but infants with very severe ROP are referred in for treatment at these central nurseries. Most of the treatment of severe ROP appears to be intraocular injection of bevacizumab, an investigational treatment with sparse evidence on long term ocular and systemic effects thus far. Visits to NICUs in Krakow were encouraging for the quality of neonatal care, but were disappointing as no ophthalmologist attended rounds or lectures.

The 6-nation Black Sea ROP workshop held in Budapest was attended by 53 stakeholders from these countries and represented an important opportunity for stakeholders from Turkey up to Ukraine. The interactions among the groups were remarkable and helpful. Those countries that were further along in development of adequate ROP programs for detection and treatment were supportive and encouraging to those from less developed regions that usually had very specific struggles, such as no lasers available for peripheral ablation (Georgia) or difficulties in coordinating care (Moldova and Romania). The attendees were eager to contribute and this effort will bear fruit with continuing support and interaction.

August 2014.

Professor Brian Darlow
University of Otago,
New Zealand



I attended the Helmholtz meeting in Moscow 2013 and visited some neonatal units at that time. It was clear that whilst there were a few highly knowledgeable and hardworking neonatologists, the care given to all preterm children in Moscow was very variable. There was very little information from outside of Moscow and St Petersburg. So I was very impressed by the proposed and actual improvements we heard about at the meeting in Barnaul.

We had pressed on our hosts the importance of including nurses in the meeting and quite a number attended the workshops, although they were not there for the presentations on the first day. I made a point of repeating my talk on the prevention of ROP through improved neonatal care for the nursing group. To me, having their participation at this meeting, felt like a great step forward. After some nervousness several of the group became very active participants and were able to bring up issues. It does seem that in many areas there is now good equipment and sound protocols for care. But at the same time there are frequently too few nurses and the nurse to patient workload can far exceed accepted international standards (1 nurse to 2 infants in intensive care and 1 nurse to 4-6 infants in level II care). This means that care will always be less than adequate. For example, even if there are sufficient oximeters too few nurses will mean it is almost impossible to achieve saturation targets for much of the time.

The other issue which was raised was the fact that many very preterm infants will stay in smaller units until around 7 days of age when, if they have survived, they are transferred to a regional centre. By this stage the less than adequate care received will already have set the scene for ROP and bronchopulmonary dysplasia plus other morbidity. Antenatal transfer of high risk mothers to a regional centre is the most optimal strategy but if that is not feasible then early neonatal transfer is essential. Whilst this would represent an organizational change supported at a high level it is one that should be lobbied for.

It was good to see some data presented at the Barnaul meeting as this will be the starting point for highlighting problems and bringing about change. My hope is that this meeting will have been something of a catalyst for supporting real change in neonatal care in Russia.

August 2014.