

If antibiotics and pancreatic enzyme supplementation would be available for all CF patients in Russia, a similar life expectancy will result also in this country.

All drugs have their price. The cost of appropriate treatment per patient for one year in Russia is approximately 7000 USD. And this figure may increase with the use of other, more expensive antibiotics to approximately 17 000 USD. It is good news that in Moscow CF patients can receive their drugs free of cost since 1999. However, such help is not offered in every part of the country and strong efforts have to be taken to improve the situation where it needs improvement. But, besides the financial aspect, particularly with antibiotics we have to pay another price. Bacteria get resistant to every antibiotic and sooner or later we have to change our antibiotic strategy.

Education of the various aspects of CF to the young clinicians in other parts of the country is mandatory. National and international symposia or congresses devoted to CF are valuable strategies to distribute and increase the knowledge about CF in distant parts of the country. The 5-th CF Symposium which starts today together with the 10-th National Congress of lung diseases here in St.Petersburg is an optimal occasion to learn from the many experts who have come here all about CF, to make new friends and to plan future scientific cooperations. Research is needed to investigate host-parasite interactions and many other aspects of the multifactorial CF pathogenesis. We have to move, to change, to modify, to create new concepts. Research is in the air and we all sense it with our hearts. Let's start together into this new era!

**Dr. Chris Rolles (UK),
Southampton General Hospitals, Southampton**

Professor Kapranov and his team are to be congratulated for the wonderful development of the cystic fibrosis service in Moscow over the last 10 years.

When Professor Kapranov started the service he encountered a great many obstacles both political and financial. He had a very loyal team who stayed with him and supported him during those difficult times. At first he needed to find a base in which the cystic fibrosis service could run. Eventually his persistence paid off and he was provided with accommodation for both the staff and the patients at the Republican Children's Hospital. In spite of having very few links with any other centre of expertise the clinic developed and patients from the whole of the country were seen, diagnosed and cared for as well as those from Moscow.

In 1993 a British based charity (International Integrated Health Association IIHA) made contact and was able to initiate a very productive collaborative programme which still continues.

Initially the collaborative programme was based on a "twinning" with the cystic fibrosis centre in Southampton which was of comparative size in terms of patients. It was immediately recognised that cystic fibrosis care in the UK could not be absolutely paralleled in Russia because of the sheer resource implications. For example in the UK at that time the average patient with cystic fibrosis cost the National Health Services about 15 000 USD per year. That type of resource would not be available in Russia and would not even be appropriate in the Russian setting. With the help of a pharmaceutical company (Solvay) a project was set up to see whether a much smaller investment in Moscow could produce results that might at least be comparable. The end point in a 4 year project was to prove that perhaps 90% of the benefit seen in the UK could be obtained in Russia with less than 10% of the resources. This was not only extremely good



news in the Russian setting but was also very important information in the UK where it was recognised that a lot of the additional expenditure was probably unnecessary. The results of that collaborative study have now been published. The essence of the modified clinical approach was based on the knowledge that the Moscow team had good training and expertise and that the British team had practical experience in the running of a clinical service.

One of the first changes in Moscow was the development of an outpatient service. This meant that children were not only seen when they were ill (and were usually admitted to hospital) but children were seen when they were well in order to keep them well and keep them out of hospital. At regular outpatient visits children were carefully weighed and measured and this data was carefully recorded on individual growth charts. With a condition such as cystic fibrosis it is very easy to see quickly if something is going wrong, perhaps before the patients or the parents are aware of this. As a result, children's use of hospital inpatient facilities was drastically reduced. There was, therefore, a change in the whole way in which the doctors worked. They now saw more children, but in an ambulatory context, and the number of beds occupied by children in the hospital was reduced from about 30 beds at any one time down to as few as 4 or 6.

An unexpected complication of this improvement centered on the fact that funding was based on bed occupancy. At first sight there could be a great reduction in the budget although the service required the same budget in order to run an outpatient or ambulatory service. These issues were to some degree overcome.

Twinning involved virtually all the staff of the cystic fibrosis service in Moscow. Doctors, nurses, laboratory staff and clerical staff all had the opportunity to visit the clinic in Southampton and conversely the Southampton staff, including medical, paramedical and secretarial staff, visited Moscow. Throughout the exchange process staff stayed with local families in order to get to know them as people and understand their lifestyles and the problems and benefits of living in each country. This was seen as much more beneficial than for example the expensive use of limited resources simply to attend conferences.

One example of such an exchange was that involving the secretary for the CF Service in Southampton, who had a great deal of experience in the way in which notes could be set out and filed and records of phone numbers and important contacts could be held. This secretary exchanged with her counterpart in Moscow and they were able to discuss the ways in which the traditional Russian handling of patients did not always make quick access to data easy. Simply using a Western style filing system with growth charts enormously improved communication and continuity of record keeping. The cost of this was within 1 USD per patient.

It may come as a surprise to outside observers that as a result of this collaboration the cost of antibiotics for cystic fibrosis care in Moscow has actually gone down while the growth and development of the children has improved to the point where the height and weight and wellbeing of the Moscow cystic fibrosis children closely matches those of children with CF in the UK. Most of the children are now attending school and because the children are well enough the mothers are often able to go back to work which was not the case in the early development of the services. Some children are having home IV therapy supervised by the specialist CF nurse.

Although detailed calculations have not been made it is recognised in the west that patients with cystic fibrosis do not usually die in childhood. Given the improved wellbeing of Russian children with CF it is probably also the case now that a newly diagnosed patient, with good care, will probably live into early or middle adult life.

The Moscow CF Team involves hospital medical staff as well as academic university staff and research is an essential part of the enthusiastic combined service. Many projects have been carried out and many are in progress. Presentations at national and international conferences are now routine.

As the cystic fibrosis team in Moscow has consolidated its service it has also been able to improve other aspects of the wellbeing of children in hospital. They have a beautiful brightly coloured ward with pictures and toys and an atmosphere where children are happy and their parents feel confident. Not only has this transformation occurred locally in the Republican Hospital but also it has now spread to the emerging cystic fibrosis clinics in over 20 other cities throughout Russia.

The Russian-Southampton CF collaboration has triggered twinning between other paediatric departments in Moscow and Southampton notably between the surgical and diabetic departments. Other CF twinings on a smaller scale have been set up between Omsk and Novosibirsk and Poole and Portsmouth in the UK. In addition Southampton has effectively used the same model in Albania and India.

Professor Kapranov and his dedicated team should be very proud of the success of their service. The struggle of the early years has paid off abundantly. They now have an internationally recognized service of excellence which is of benefit to children with cystic fibrosis throughout Russia and provides a model of good childcare which could provide lessons for any developing paediatric service.