



Child Health International

The Final Report of the outcome of a visit to the
UK by a team comprising medical professionals
and a parent representative from Vilnius,
Lithuania, with special interest in cystic fibrosis.

3rd to 9th February 2008

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Appendix 1 Visit Programme

Abbreviations

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| CHI | Child Health International |
| CF | Cystic Fibrosis |
| CFT | Cystic Fibrosis Trust |
| PSG | Parents' Support Group |
| RBH | Royal Brompton Hospital |

1. Introduction

This report records the planning and execution of a programme, centred on the Royal Brompton Hospital, London, the aim of which was to share experience of the care of children and young adults with cystic fibrosis (CF). The report highlights the outcomes of the visit and tries to identify realistic forms of short and longer term support between CHI, the RBH, the CF Trust in UK and those determined to optimise the care of young people with CF in Lithuania.

2. Purpose of the visit

On behalf of CHI, Brandon Taylor as Project Manager, had undertaken an exploratory visit to Vilnius in December 2005 and this was followed by a more substantive visit to Vilnius in March 2006, when the professional medical advice on CF was provided by Dr Ron Knight of Frimley Park Hospital, Surrey, and a useful exchange of knowledge took place. It had always been a part of the overall plan to invite medical professionals from Vilnius to the UK as the next step; and it was foreseen that attention would be given to some particular aspects of CF healthcare: -

- a. The teamwork (Doctor, physiotherapist, dietician, specialist nurse and psychologist) approach
- b. Specific physiotherapy for children with CF
- c. Dietary advice
- d. Building up a viable Parents' Support Group in Lithuania.

3. Details of the visit

Preparations for the visit began in April 2007 and mainly involved liaison between Associate Professor Sigitas Dumcius of the Vilnius University Clinic, Professor Andy Bush of RBH and Tony Wolstenholme of CHI. With a letter of invitation, Professor Dumcius was requested to complete a questionnaire about CF in Lithuania and the resources at his disposal to provide a service to children and their families.

Professor Dumcius was invited to select a team of 4 or 5 medical professionals, to include one Doctor in his team specialising in CF, a physiotherapist, someone to offer dietary advice and a representative of a potential Parents' Support Group (PSG). Though using an interpreter was not ruled out, it was recommended that the individuals chosen should have a fair command of English. The team identified consisted of: -

Professor Sigitas Dumcius
Dr Nomeda Jokubaitiene 'CF Doctor'
Dr Ramunas Leisys Physiotherapy
Mrs Vilma Narkuniene PSG

Professor Andy Bush agreed to host the visit with his team at RBH and mutually convenient dates for the visit to London of 3rd to 9th February agreed.

On behalf of CHI, Rod Halls and Tony Wolstenholme, Trustees, managed the project.

Flights were booked on-line with Lithuanian Airlines. Accommodation was reserved at the RBH's Hall of Residence. A visit to the Cystic Fibrosis Trust in Bromley was arranged for 6th February. A small daily allowance for living expenses was given to each visitor. The RBH required a copy of each person's CV and completion of Health and Observer questionnaires - all this would ideally have been done before arrival at RBH.

The programme at RBH was drawn up by Jackie Francis and is attached at Appendix 1. It allowed attendance at 3 CF clinics and a pre-clinical multidisciplinary meeting, time with in-patients and separate sessions with each of the members of the 'team' - from the physiotherapist and dietician to the psychologist and consultant nurse overseeing the transition from paediatric care to adult care.

4. Observations

4.1 General

The Lithuanian Team faced a busy, varied and demanding week at the Royal Brompton Hospital. They were in unfamiliar surroundings in a busy teaching hospital which, rightly, made few concessions to their presence and the issue of language in particular.

In practice, however, they quickly mastered the situation and were soon able to contribute effectively and to seek answers to questions, which arose.

The outcome was a fulfilling and productive experience for all concerned. Understandably, they were most appreciative of the exposure to clinical practice but also felt they learned about organisational issues, and aspects of public awareness and the political context. They also had useful suggestions as to how further visits could be organised even more effectively.

4.2 Observations - the details

4.2.1 Clinical Practice - hands on

Given the composition of the group it is not surprising the Team found their exposure to clinical practice and real cases most rewarding and interesting. With the correct vetting procedures having been completed in advance, all members had the opportunity to attend both cystic fibrosis and general pulmonary clinics, sit in on multidisciplinary clinical review meetings and visit ward areas. Two of the members also attended specific sessions with physiotherapy staff.

The three clinicians were given the opportunity for hands-on experience and, thereby, the opportunity to contribute to the discussion of individual cases with patients, parents and hospital clinical staff.

Much of the clinical practice and diagnosis was familiar to the clinician members of the Team but for the parent member this experience was especially interesting.

4.2.2 Clinical Practice - comprehensive and integrated

However, it was the way in which the clinical practice operated and was delivered which proved most instructive. Our visitors were most impressed by the extent of teamwork and integration, which characterised the whole approach to care at RBH. Apparently, this is much less evident in Lithuania as they do not have the same range or numbers of professionals available in their system in support of CF. They have no access to psychologists, specialists in physiotherapy, domiciliary care or dietetics, and have no process which manages the important transition from child to adult services - not least, at present, because the age expectancy in Lithuania is still low by comparison with the UK.

As the Team learned, in practical terms the RBH approach means, firstly, that parents and children themselves are fully involved in discussions about all aspects of their care at the hospital (inpatient and outpatient) and in the community with the most appropriate professional.

In the hospital setting the integrated approach means the patient will be seen by all relevant staff on the same occasion, in the same place, giving maximum opportunity for parents, patients and staff to discuss and agree together the best way forward.

The Team were especially impressed by the atmosphere they found in the outpatient clinics, which they described as relaxed, informal and friendly with everyone having the chance to make a contribution in the best interest of the patient.

The Team were struck, therefore, by the richness of potential treatment regimes, complemented by the full array of antibiotic and enzyme therapies, contemporary physiotherapy, nutrition and so on. They do experience problems in securing full funding for these in their own system especially during the transitional period when patients become adult.

4.2.3 Observations - Organisational issues

On their first day the Team had the opportunity to sit in on a multidisciplinary team meeting consisting of consultants, junior and senior medical trainees, specialist nurses, psychologists and administrative staff. Chaired by Professor Andy Bush this meeting reviewed about 40 cases and discussed and agreed the most appropriate next step, and by whom, for individual patients.

In general terms such an approach is common practice in most health systems but again the Group commented on the range and number of staff involved. They did express the view that it would have been more useful for them to have attended such a meeting nearer the end of their time when they would be more familiar with processes, individuals and terminology.

This is clearly something CHI should take account of when designing future exchanges.

The extent and interrelationship of the variety of services available in the hospital and elsewhere calls for a high degree of organisation. The Team commented on how well systems such as clinic arrangements, essential components such as note keeping and medical records, and communication with parents and others, worked in practice. They noted that a senior manager was an important member of the CF team.

Underpinning the whole service at RBH, as a means of ensuring consistent standards, is a very comprehensive set of guidelines (Clinical Guidelines: Care of children with Cystic Fibrosis 4th Edition 2007), covering all aspects of care. The team each took a copy. CHI has learned that even since their return home these guidelines have already been put to practical use by staff on the ground in Vilnius.

4.2.4 Observations - publicity, information and politics

Mid-week the Team spent several hours at the headquarters of the Cystic Fibrosis Trust in Bromley, and this proved to be rich source of information and inspiration especially in how to create an effective mix of accurate information, effective publicity, and political profile.

There are over 8000 CF sufferers in the UK who, largely as a result of the work of the CF Trust, have been mobilised, with families and other supporters, into a serious force for change and improvement.

In Lithuania there are only 100 cases, nearly all children, although this may underestimate the total by up to 100%. Nonetheless, there is a desire among parents and families of these children to organise themselves and bring pressure to bear to secure improvements.

The Chief Executive of CFT, Rosie Barnes, set out in considerable detail the extensive range of activities of the Trust. In particular, she gave many examples of campaigns and appeals designed, usually with considerable success, to publicise the issue and so elevate the profile of Cystic Fibrosis and to raise large amounts of money. This was then spent principally on research to find ways to palliate the disease but with the ultimate aim of finding a cure.

The Trust worked hard, in tandem with clinical leaders in the field and CF sufferers, to develop and maintain a very high political profile. As a result, it had established itself as an accepted and respected arbiter of clinical standards in the UK, visiting hospitals and centres, principally to encourage best practice but ultimately to threaten exposure where serious shortcomings were not addressed.

Their website (www.cftrust.org.uk) is a rich source of advice on all aspects of CF and they were happy to support translation of any material into Lithuanian subject to appropriate quality assurance.

Translating the work of a large, powerful UK charity, with significant financial and political clout, into the Lithuanian environment would not be easy. The Team recognised they were starting from a low base but were greatly encouraged by what they heard and saw. They now need to identify practical ways in which they can start to make progress and how other agencies can best help them. Consultation with the Parent Support organisation in neighbouring Belarus might be one option.

In terms of developing means of communications and mutual support, such as on-line forums, it was believed that only a minority of CF parents/families

currently had access to the internet in 2008 and therefore other complementary strategies would also be necessary.

Information is an important weapon in the prosecution of the Trust's aims. CFT manages a comprehensive database - a gift from the American CF Foundation - covering most of those with CF in the UK. The database contains anonymised demographic and clinical data, regularly updated and profiled. How this differs from the registry promoted by EuroCare CF is unclear.

The Team were given hard copy details of the database and invited to consider whether they would like to use the system (subject to assurances about security and confidentiality). This would enable them to compare the well being of their children - in terms of follow-up of pulmonary therapies, respiratory microbiology, pulmonary assessment, nutrition, laboratory data, complications and the results of annual assessment - with that of children in other countries.

The CF Trust has also collected data demonstrating the cost effectiveness of outpatient and community health care for children with CF when compared with long periods of hospitalisation. A copy of this data was passed to the Team for possible application in Lithuania.

In short, it was clear that harnessing political support was critical to the success of any strategy for improvement. The CFT had relevant experience in Poland, together with contacts elsewhere in the European Community, and offered its assistance in developing such a strategy. CHI needs to consider how it might assist in that process.

4.2.5 Observation - the practical arrangements

Accommodation for the team was entirely adequate. The only comment was that it would have been helpful to have information in advance so they could make decisions about what to bring. Additionally, in ideal circumstances the necessary vetting procedures (CV, confirmation of personal identity, Health and Observer questionnaires and clearance) would ideally have been completed before arrival at RBH.

However, the Team's most important comment about the timetable was their wish to have even more clinical exposure as they found the practical sessions most useful.

As mentioned previously attendance at a multidisciplinary meeting would probably have been more productive for them later in their week; but, obviously, the timing of this is fixed by hospital considerations and in this case always falls on the Monday.

The visit to CFT was very welcome and gave a much fuller picture of CF in an albeit very different culture. It also opened the way for ongoing practical assistance with the database exchange, translation of supporting information, fund raising ideas and how to pursue the political strategy. The Team obviously needs to think about how to take these ideas forward and CHI will be pleased to assist in that process.

5. Action

Considerable thought now needs to be given by all involved to how the issues raised by the visit can be progressed most effectively. Certainly, Professor Bush has expressed a willingness to offer a twinning link between his department at RBH and the Team at Vilnius University Hospital. But, in particular, the Team from Vilnius need time to consider the possibilities among themselves and with other colleagues.

CHI is there to support the whole process but not to be presumptuous. The list of actions suggested at this time is therefore deliberately short and for debate and agreement. It is likely that further steps and opportunities will be identified in the future and a review of progress should be undertaken by CHI within six months of the visit.

5.1 Action short term

Identify Physiotherapist to come for intensive course at RBH (*already actioned March 2008*)

Identify how to activate the CFT database

Practical steps to help the parent group to get going

Action by CHI to improve working arrangements of further visits

5.2 Action longer term

Agree political strategy with CFT/CHI and others

Longer term strategy to maintain and develop parent group

Plans for ongoing twinning arrangements

6. Conclusions

The purpose of the visit was to provide information, advice and support for those involved in the provision of CF services in Vilnius to help them improve clinical care for their patients. To judge by the comments of the team members this objective was fully achieved.

The differences and difficulties are considerable but significant progress is clearly possible. The next steps, taking a lead from those in Lithuania itself, are to identify the practical actions to maintain and hasten that progress. Professor Bush is keen to develop the twinning arrangement and will be visiting Vilnius again mid April 2008.

CHI's role is to facilitate and support that process of improvement in any way it can, given its limited resources as a small charity. The visit to RBH, costing a few hundred pounds to organise, has clearly demonstrated just how valuable, welcome and productive such an approach can be. CHI will be working with all concerned to ensure progress on the actions identified above will be taken and a review of that progress will be undertaken mid 2008.

February 2008 Final report TW/RH

Acknowledgements

Child Health International wishes to thank Professor Andy Bush of RBH and his team - Linda Kapojieva, Jackie Francis, Nicola Collins, Rivanna Stuhler, Michelle Puckey, Angela Clarke, Su Madge - and all those who helped the visit to run smoothly at RBH. CHI thanks Rosie Barnes, CEO of CFT, and all her friendly staff, for a most helpful insight into the impressive work of the Trust.