

# **SPECIAL EDITION**

**August - September 1996**

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## **IIHA MOVES TO NEW ADDRESS - BUT THERE'S A DROP IN FUNDING**

We have moved to new offices on the spacious top floor of the former rectory of St Thomas's Church, Winchester. At this altitude above the traffic jams, we can breathe more freely and there's a wonderful view over the roofs of the city to the cathedral and beyond to St Giles Hill.

We were sorry to have to leave our old offices in the Square, which the Winchester Council had so generously provided for us at a very small rent. Now we have to pay a more commercial rent, but just at this time when we need extra support for our work to help chronically ill children in Russia and the Ukraine, the Foreign and Commonwealth Office Know How Fund (Small Partnerships Scheme) has turned down our request for funding an extension of our programme in Russia to introduce "outreach" work to the Republican Children's Hospital. In all respects our Cystic Fibrosis (CF) project has been a success. Now we are embarking on a programme which includes training specialist cystic fibrosis nurses, who will visit the families of children with CF. This



IIHA is on the top floor.

is an important initiative in a country with weak social infrastructures.

A great many people, including doctors at the Republican Children's Hospital and families of children with C F are going to be disappointed. We have been so consistent and reliable in the help we have offered. Our Russian colleagues are doing a lot for themselves now, but they still need a great deal of help, particularly with the development of specialist nursing and the family support services.

One of the main problems, of course, is that there are virtually no social services as we know them; and this is one of the principle reasons why the Know How Fund

has turned down our request for a grant. They describe our plans as "premature" even though we are getting quite a lot of support in Russia from the families of chronically sick children and their doctors.

#### **Encouragement from Europe**

On the other hand, the E.U. is encouraging our initiative in trying to help families who are socially disadvantaged through the chronic illness of a child. Family support groups are already established in Moscow and in various regional centres in Russia; but they do need a lot of help from us so that they can eventually help themselves. The Russian Health Ministry and the Ministry of Social Protection are taking a close interest in what we are doing.

It is surprising that the Foreign and Commonwealth Office do not seem to understand how much has been accomplished and do not appreciate the extent of the changes that have already taken place, as the result of our initiative, in the management of cystic fibrosis. Recent tests show that there has been a vast improvement in the health of many of these children with an improvement in the morale of patients, parents and doctors.

We have kept the Know How Fund informed of our progress and plans for the future, so the only explanation for their decision not to continue supporting us must be that our reports are not being studied very carefully, or that they are short of money.

#### **The next training visit to the UK**

We are keen to get on and invite one or two of the specialist nurses plus the young doctor, who is looking after CF adolescents and adults in Moscow's Republican Children's Hospital, for intensive training in the U. K. This programme will cost no more than £3,000. If there are 30 of our supporters and/or Friends Meetings, who could help with a donation of £100 each this would solve the problem. Since the Know How Fund is not helping us, there is an urgent need for this money now.

We have applied again to the E.U. Phare/Tacis LIEN Programme, which has funded our work in the Ukraine, for financial help in Russia. Our applications have been selected as qualifying for grants for our social programmes to help (1) children suffering from cystic fibrosis and their families in Russia; and (2) children suffering from heart problems and their families.

Both these groups are socially disadvantaged because of a chronic illness in the family. The mother usually has to remain at home to look after the child and the father earns on average about £50 a month, of which £20 or more goes on the rent for the family's apartment.

#### **Quakers in Moscow**

The Quakers in Moscow have been a great help. They have organised an annual party for children with CF, commissioned a Russian artist to paint murals to brighten up the children's ward at the Republican Children's Hospital, and have helped with counselling for the families and setting up family support services.

Patricia Cockrell, who has been involved in the setting up of the Friends Meeting House in Moscow, and has worked with us in Russia and the Ukraine, is now returning to her home in Exeter, but has offered to continue to work with us.

"I do so want to maintain my connections with Russia," she told us. "I could not bear cutting myself off now when there's so much I can do."

**Please note our new address:**

**INTERNATIONAL INTEGRATED  
HEALTH ASSOCIATION**  
*Registered charity No 1014734*

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#### **Ecumenical development**

Our work is becoming really ecumenical with the Catholic Apostolic Office in Moscow also offering to help the CF Programme by providing a centre (Blagocentre) for the family support services. The new building, whose construction was financed by the Catholics, was recently completed. The Moscow City Council provided the land for the building. If we are able to obtain the necessary funding from Europe, IIHA will be offered offices in this building. The centre is under the overall direction of Father Stefano Caprio and the medical director is Dr Nikolai Fomine, who visited us recently to study the way we run our family support services and the hospital "outreach" programme in Southampton.

### East European Partnerships

We are also hoping to work on joint projects with the East European Partnership (EEP), which is associated with Voluntary Service Overseas and is supporting initiatives to strengthen the development of social institutions in Russia. As a small example of EEP's work in this area, one of their volunteers has begun a twelve-month placement as a social worker in Ekaterinberg.

### Improving the delivery of health care

Dr Chris Rolles, consultant paediatrician at Southampton General Hospital, who has directed the IIHA/Southampton/Moscow CF medical programme since 1993, says: "One of the issues that I have thought about increasingly over the past few months is that possibly the most important thing we have to offer Russia is our expertise on how to deliver health care. This is



quite different from the content. Teaching doctors the technology, or simply about what new drugs can do, is very easy. Teaching them the way in which we deliver health care and getting them to change their culture of health care is much more difficult."

A start has been made on this with the introduction of record-keeping, such as growth charts and patients' notes and changes in the management of the CF clinic. Instead of the usual crisis medicine, which meant only seeing patients when they were seriously ill, the hospital has now set up regular follow-up clinics. The object is to keep the children well and to watch out for any signs of deterioration in their health.

There is, however, still a long way to go in teaching the Russians health care management in a hospital setting, including such things as the management of time, personnel, research etc.

"There is still relatively little planning within the CF team in Moscow," says Chris "and as far as I can see, none in the health service as a whole."

### Siberian CF Centre

Chris recently visited Novosibirsk in Siberia and was invited to take a look at the children's hospital there. Most of the wards were grey and cheerless, but to his delight he found the ward for children with CF had murals, colour and toys and the staff had a very positive attitude. The CF parents had formed their own support group.

"The two doctors running the service are total converts to the work we have been doing in Russia," says Chris.

Drs Natali Romenko and Dr Irene Zaidman had attended the CF conference in St Petersburg, which members of IIHA attended, and had also taken part in the Moscow conference last November which was organised by IIHA's partner in the Republican Children's Hospital.

### CF Specialist nursing

Judi Maddison, the CF specialist nurse at Southampton General Hospital, went to Moscow in November, 1995, to look into the possibility of developing the Republican Children's Hospital outreach services. She reported on the many difficulties involved in setting up an outreach programme, including the poor communication between polyclinics and the hospital. She also found schools reluctant to co-operate in CF educational programmes.

However, Judi was impressed with the changes that have taken place in the hospital since she was last there two years ago.

She found many positive aspects of the CF service.

"The CF staff now work as a team," she says, "and things they told us would be impossible are now set up- patients' notes being a good example. The change in attitude has created a completely different working environment."

Judi was encouraged by the support there is for the idea of a roving specialist, who would not only give emotional support to families from diagnosis onwards, at times of greatest need, but could act as a line of communication between the hospital and polyclinic.

IIHA is trying to obtain a car for the specialist nurse and is also planning a seminar for polyclinic and hospital doctors to discuss ways they can co-operate. We are also hoping members of the U.K. Royal College of General Practitioners

International Committee will take part in a seminar on improving primary health care so that there is more co-operation between polyclinic and hospital doctors and more home visits. After having been turned down by the Know How Fund (SPS) much will depend on the support we obtain from the European Commission and from individual well-wishers.

#### **Community-based child health care.**

I was greatly honoured to be invited to take part in a paediatric conference in the prestigious new children's diagnostic and treatment centre in Odessa in May. Paediatricians from Spain, Italy, the USA, Israel and France presented papers and some of us took part in a TV discussion on children's health care needs.

I presented a paper on IIHA's community-based child health care strategy. Our work with CF children and their families is a good example. CF is one of those chronic illnesses that affect everyone in the family, often leading to the most distressing of economic and emotional problems. Also, as CF patients reach adolescence, there are interpersonal conflicts between parents and their adolescent son or daughter, and between doctor and patient - which, of course, is normal in adolescence, but exaggerated in the case of a chronic illness.

#### **Ukraine social programme**

Our social programme in the Ukraine has been supported by the European Union. At the outset it was made clear that the IIHA project must comply with the LIEN Programme aim, stated specifically as follows:

To develop sustainable social and health programmes where existing infrastructures and services are weak in order to help disadvantaged target groups. In our case, the target group is children with CF and their families.

It is accepted nowadays that the most effective organisations are those who have a clarity of vision which is shared by all its members.

IIHA's approach is an holistic one, which includes organ specialities, but looking at the patient as a person who has social, spiritual, psychological and educational needs-which the psychologist Abraham Maslow described as "being needs"- we support a system of total care.

In paediatrics physicians now concentrate more on positive health than illness in children. Dr Chris Rolles, consultant paediatrician at Southampton

General Hospital, has described this approach as follows:

In paediatrics it is now accepted that the doctor must look at the child in the context of the total health and well-being of developing human beings from conception, through pregnancy and birth and then through childhood and adolescence and on into adult life. Paediatrics is no longer regarded as a branch of adult medicine, but more the other way round: i.e. the study of what happens early in life as an explanation of conditions that develop later on or as an essential aid to understanding the health of the human being at maturity.

Our project, *Health of Future Generations*, which has not got off the ground yet through lack of funding, is mainly concerned with pre-conception care with its object of ensuring a healthy pregnancy and a fit child, with parents who, understanding the needs of childhood, provide models of healthy living for their children.

Our work is not, as the Know How Fund (SPS) said, "premature" -on the contrary, it is undoubtedly exactly the right time to introduce programmes of total care, which look to the future in a positive way. Our programme is not so much about repairing damage but more about creating systems of health care that go beyond the treatment of sickness.



A strategy for child health care must distinguish what the health service can achieve in both providing health care and promoting health and then setting out clearly what other departments, such as departments of social protection, the environment, public health, education and industry, and other agencies can achieve in the promotion of child health care in its widest sense. The welfare of the family, the reduction of stress, in which complementary therapies can play a part, training in diagnosis, screening, and treatments must be accompanied by hospital outreach work and the training of NGOs in family support, public relations and self-help. This is the strategy IIHA supports and is trying to put into practice.

Roy Ridgway