

IIHA

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News

Practical steps towards healing
people in a damaged world

To all members, old and new,
WELCOME.

We've tried to make this newsletter chatty, personal, like a letter to a friend - with a bit of this, a bit of that, not the whole story, but enough to give you an idea of the scope of our work.

Lots of interesting things are happening. Lots of depressing things too, of course, because we are working in Eastern Europe, with its long history of persecution and injustice from which over 160 million are now struggling to emerge. But, as Blake said, "joy and woe are woven fine." Every day letters fall on our mat which say the same thing: "Sorry, we receive a great many appeals and have to turn down some very worthy ones like yours". But, in spite of all the rejections, we keep writing appeals every day, encouraged by the odd letter we get with a cheque and sometimes a few kind words such as those recently written by Jean Simkins, Chair of the Economist Group Charities Committee, who said:

The Committee found your letter about the work of your Association with your Russian partner at once hopeful and horrifying. The enormity of the problems before you, and the fact that their impact is on the rising generation (and therefore still to be fully realised) made the Committee keen to help.

And another encouraging letter came from Dr Caroline Collier, Senior Medical Officer, the International Relations Unit, the UK Department of Health:

May I say how delighted I am that the medical care (and thus life quality and expectancy) of 300 Ukrainian children will be improved as a direct result of IIHA's willingness to assist one child with cystic fibrosis.

Caroline was referring to a letter appealing for help to the Department from the sister of a twelve-year-old Ukrainian girl, who is suffering from cystic fibrosis, a life-threatening disorder. We offered to go to Odessa with a doctor from the Brompton Hospital, London, to see if there was anything we could do to help. Fortunately, we were able to say yes, we were sure we could help. The UK Department have offered to finance medical exchanges, but we need a lot more help to buy modern pancreatic replacement enzymes which CF children desperately need but are not getting in the Ukraine. We are solving the problem in Moscow. We must do the same for Odessa.

The last lines of Blake's poem following "joy and woe are woven fine" are:

And if this we rightly know
Safely through the world we go!

Attitudes matter a great deal when you're faced with the sort of problems they are facing in Eastern Europe today.



St George and the dragon: Moscow city coat of arms

Odessa: Teaching and resource centre for cystic fibrosis ?

Dr Mark Rosenthal, consultant chest physician at London's Brompton Hospital, accompanied Roy and Dorothea Ridgway to Odessa. They visited the Black Sea port from 10-24 October with the aim of carrying out a feasibility study at the Pirogov Medical Institute on ways in which the Brompton can co-operate in improving the care of cystic fibrosis patients.

The 300 Ukrainian CF children are not currently treated with modern enzymes and antibiotics, and knowledge of modern methods of physiotherapy is also lacking. The result is all the children suffer from very poor health.

Children die by the age of 10

The UK Department of Health financed the visit knowing of IIHA's work with Southampton General Hospital and Moscow's Republican Children's Hospital, where 40 CF children have been receiving modern treatment for a year with excellent results.

Professor Boris Reznik, who is head of the Paediatric Department at the Pirogov Institute in Odessa, is aware of exactly what is required and he and his colleagues have the necessary skills but lack the facilities. The majority of Ukrainian CF children die by the age of 10, but could live up to the age of 40 years with UK quality care. The Children's Municipal Diagnostic Centre, Odessa, has been donated by the local health authority to provide a diagnostic and daycare/out-patient facility with in-patient facilities for 12 CF children.

Dr Janneta Krainiaya and Professor Reznik have been

invited to attend the Brompton Hospital to observe and take part in the management of UK CF children.


IIHA would be responsible for fundraising and the logistics of medical exchanges. These would teach and demonstrate the principles of long-term care for CF children and monitor their growth and lung function. As in Moscow, record keeping for each visit would be introduced, as well as parent held records to provide communication between Odessa and the local health facilities. A parents group would be organised to provide mutual support and education, to raise CF awareness in the local community and to act as a lobby group in government.

(There is already a registered charity, the Ukraine Cystic Fibrosis Trust which will be working closely with IIHA in fund raising, lobbying, organising parents exchanges with Britain and in making world-wide contacts, provided that the project can be financed).

Model of child healthcare

It is expected that the Paediatric Department of the Odessa University Pirogov Institute will become more adept at the management of CF and serve as a teaching and resource centre for the Ukraine. Morbidity and mortality of children with CF should be reduced. The model of central and parent held records, and increased family involvement, combined with improved pharmaceuticals can be used in approaches to other chronic diseases of children (diabetes mellitus, renal disease, malignancies etc) in the Ukraine.

ISABELLA BLOCK



Ukrainian mother with her little boy who has cystic fibrosis

IIHA DIRECTOR & TRUSTEES

Roy Ridgway, Founder of IIHA, Director

TRUSTEES

Dr Jean Robertson MB ChB General Practitioner St Albans, Co-founder of St Albans Hospice Care Team and St Albans Cancer Support Group (Chair)

Dr Alistair Cameron MB ChB MRCGP, Senior Medical Officer Dept of Health, formerly Medical Director, Wakefield Family Health Service

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To the parents of CF patients

Dear Friends,

We are a group of parents who have children suffering from cystic fibrosis. We appeal to you for help.

Nowadays, due to the disastrous economic situation in our country, the state of health of our children who have suffered since early childhood has deteriorated significantly. We are in despair! There are no drugs for treating our children, no pancreatic replacement enzymes that are essential to their health, no appropriate antibiotics. The children are emaciated and are in physical development behind normal children of the same age. They are deprived of the joys of childhood.

The medical staff of the only Ukrainian centre for treating CF do their best in the circumstances but lack the finance and resources to introduce modern treatments which would vastly improve the quality of life of these patients.

This year we have founded a charity called the Odessa Children's CF Trust. Unfortunately, this has not yet brought the desired results. It seems nobody wants to help us.

If you can, please help. Any help will be accepted with great appreciation. Only in an atmosphere of sympathy, love and consideration for each other can we survive our present situation.

We hope for your friendship and understanding.

К родителям детей, больных цистозифброзом

Дорогие друзья!

К Вам обращается группа родителей детей, больных цистозифброзом.

В настоящее время, в силу тяжелой экономической ситуации в нашей стране, положение наших детей - инвалидов детства, - резко ухудшилось. Мы доведены до отчаяния! Лечить детей нечем: нет ни активных ферментов, ни действенных антибиотиков. Дети часто истощены, отстают в физическом развитии, лишены элементарных радостей детства.

Врачи единственного в Украине Центра по лечению CF лишены возможности оказать эффективную помощь из-за отсутствия средств, хотя делают все возможное в этих условиях.

В этом году мы объединились в общественную организацию - Одесский Детский Фонд Муковисцидоза (Цистозифброза). Однако, это не принесло пока облегчения. Помочь нам никто не хочет.

Если можете, помогите нам! Любая, самая маленькая помощь будет принята нами с величайшей благодарностью. Только в сочувствии друг другу, внимании, любви можно выжить в нынешних условиях.

Мы ждем Вашей дружбы и очень надеемся на понимание.

The original letter, signed by 24 parents, is in our office. If you would like to help, write to Dorothea and Roy Ridgway, ИНА, 3 The Square, Winchester, SO23 9ES

The tree-lined streets and beautiful people of Odessa.

I've always had a romantic idea of Odessa as my parents had a school there years ago. They had many tales to tell - and I wasn't disappointed.

Wide, tree lined streets, architecturally beautiful buildings, mostly crumbling, and warm, intelligent, loving people uncontaminated by capitalism - as yet.

We visited the children's department of the Pirogov Hospital with Mark Rosenthal from the Brompton Hospital, who came with us. The 200 students sitting round in white caps and gowns in the lecture theatre were most impressed with the English doctor who refused to wear a white coat and knelt on the floor in his immaculate suit examining the children.

Later we had meetings with the parents. They are all depressed because of the lack of medication or treatment for their children. They are all aware that their children's lives will be very short if they don't get essential enzymes from the West. One of the doctors there is also a director of the Institute of Traditional Medicine. We have put him in touch with the Medical and Scientific Network and hope to make him a member of the COST B4 project in Brussels which is looking into the economic benefits of complementary therapies and the possibility of integrating the most effective into mainstream medicine. The Russians don't see this as a problem. To them whatever works is OK.

As English people we were a source of interest and amusement. We were looked after by Igor, a medical student only a year off graduation, who speaks English, and Yuri, second in command in the transport firm run by Oxana Govorovskaya. Oxana was the person who first contacted us about her little sister Olga, who suffers from CF.

Our hotel was in the grounds of a sanatorium where families with children from the Chernobyl region are sent for a month each year to benefit from plentiful food and wonderful air which made them and us sleep like babies.

A walk along the coast brings you to Mother-in-Law bridge. A Count in the 17th century built this bridge to cross from his castle to the opposite side of a gorge to where his mother-in-law lived and he went to see her every day so the story goes. It wobbled a bit.

We visited Alexander Kovetski, the public health officer in the Ukraine. We could see the sea from his office on the 14th floor. He was keen to invite experts from England to advise on primary healthcare reforms.

The tenor of the place everywhere we went was relaxed, unhurried, unlike most cities; the Mafia who descend on other cities don't seem to be interested. We didn't see beggars either, except at the gates of St Nicholas Church where Mark was told off for taking a video film of a procession of priests, with their long beards and gowns as they moved slowly towards the church. A bell ringer, up in the belfry stood precariously between the enormous bells. How he managed to make them peal without being struck himself I don't know! Just down from St Nicholas was the sea, and on the other side rows of beehives.

It's a lovely place. We came back via Vienna where we had to change. Suddenly there was everything you need and don't need. Always a relief to get home where you don't have to worry about medicines when your children are ill.



The golden lion in the grounds of Sanatorium Sholova, where we stayed

REMARKABLE BEGINNINGS

The way in which IIHA has developed over the last year or two is remarkable. We started off with fundamental approaches to health, giving priority to reproductive health which we thought was the one most likely to attract funding. We called this project The Health of Future Generations - because the health of a child starts with the health of parents at conception; and this can affect at least two generations. We were also involved with the Sechenov Medical Academy in the integration of effective complementary therapies into mainstream medicine. As an expression of our concern for the environment we initiated an annual conference on Health in the Workplace. All these have progressed, but the project which has leapt ahead is one which simply arose out of a painful but rich experience of Roy and Dorothea Ridgway, that of caring for a much loved and talented son who suffered from cystic fibrosis and died at the age of twenty-nine after a wonderfully creative life.

When visiting Moscow in April 1992, Dorothea said, "Wouldn't it be marvellous if we could help just two or three children with cystic fibrosis and their families?" This was the small beginning, which has led to the major and growing projects which you can read about in this newsletter.

And there has been a second small beginning in the Ukraine, which started with a letter from the sister of a child with cystic fibrosis, referred to in the editorial, and has led to plans to assist CF children and others in Odessa's Pirogov Medical Institute.

But what has happened has even wider benefits. Through running the CF project in Moscow, IIHA and the doctors working with us have realised how much the Russians need experts to advise them on health management, particularly in the case of chronic disorders in children. This has become the main focus of our work with CF children which we are planning to extend to other departments of the Moscow Republican Children's Hospital and Odessa's Pirogov Medical Institute. We are providing models of integrated health that it is no exaggeration to say could spread around the world. It seems that healing begins with the knowledge and sympathy born of direct experience, particularly if it involves pain.

SIMON HOUSE

A THRIVING PARTNERSHIP WITH THE SECHENOV MEDICAL ACADEMY

Michael Dibdin describes our continuing dialogue with Prof Zilov's Non-drug Therapy Department and steps being taken to obtain charitable status for IIHA in Russia.

A great deal of what Integrated Health is doing today has resulted from its close relationship with Professor Vladimir Illyn and the Department of Non-drug Therapy at the Sechenov Medical Academy in Moscow, Russia's oldest medical teaching institution. This relationship continues to thrive and this June Professor Vadim Zilov, Professor Illyn's successor, and his chief scientific research assistant, Dr Ludmila Koudaeva, came on the Sechenov's third delegate visit to this country. The centrepiece of the visit was a two day conference on complementary medicine organised by the Research Council for Complementary Medicine on behalf of the European Community Committee on Science and Technology at the Strand Palace Hotel in London. This was a great success, attracting some two hundred delegates from nineteen countries and a truly international platform line-up including speakers from the United States, the United Kingdom, Germany, Italy, Denmark and Slovenia.

Complementary therapies research

The conference focused on the main issues concerning the integration of complementary therapies into mainstream medicine, including meaningful research procedures, effectiveness, shared language and perceptions, economic and legal issues, availability of research materials and so on. It turned out to be an opportunity to make new connections and meet old friends as well. Among the participants were Midge Whitelegg, our medical herbalist on the CF project in Moscow, and Dr Jane Springett, our partner from Liverpool John Moores University on the Health in the Workplace Project. The lectures were rounded off with some lively and stimulating open seminars on a whole range of subjects - cancer, energy, self-healing, research techniques, databases, psychological intervention to name but a few. The conference had proved an ideal setting for both information and discussion.

Participation in the conference was the prelude to a whole range of visits and meetings designed to give our guests a good insight into the current state of complementary medicine in this country. Highly successful meetings were arranged with the British Medical Association, the Royal College of General Practitioners, the Institute of Complementary Medicine, the Association of Reflexologists and the National Federation of Spiritual Healers. The visits included a most enjoyable and instructive overnight stay at the Yoga for Health Centre in its idyllic setting in Ickwell Bury outside Biggleswade where the visitors received a warm welcome from the founder, Howard Kent, and his colleagues, and visits to Dr Jean Roberton in St Albans (complementary approaches in psychiatry), and to the Bristol Cancer Help Centre for a presentation by the medical director, Dr Rosy Thompson.

Time for relaxation

Amidst all this activity time for relaxation was not overlooked and apart from sightseeing (and shopping!) in London - from the glories of the rose garden in Regents Park to the funfairs and fireworks of the Tower Bridge Centenary celebrations - our visitors were entertained by Roy and Dorothea and the "team" down in Winchester including a drive through the New Forest and lunch in Lymington. After that experience, another seaside visit proved irresistible and the trip to Bristol was followed by a short stop for ice creams in the unspoilt and peaceful setting of Clevedon on the Bristol Channel. Their stay was rounded off with a splendid Renaissance Group party at Lena's in the Barbican. The whole visit was a great success and thanks are due to George and Mary Sudbury for providing accommodation in Winchester and a very special thank you is due to Mrs David Wright for making her flat near Marble Arch available to the visitors for the whole of their stay in London.

The Russians' visit provided an opportunity to lay foundations for an Integrated Health branch in Moscow, to initiate and vet projects, to help with communications and liaison especially with the Russian Ministry of Health, and in general to create a closer and more secure bond between us. This was taken a further step forward with the visit in the Autumn of Dr Larissa Skuratovskaya, a close friend of Professor Zilov and Dr Koudaeva, and an important figure in the Russian medical establishment and the international women's movement in her own right, who will join the Integrated Health team in Moscow. Steps are now being taken to obtain corporate status for Integrated Health in Russia.



Pour la Naissance du surhomme by Frances Pierre Yves Trenois

Activity in London continues apace. The International Department of the Academy has been provided at its request with details of the medical faculties of Oxford, Cambridge and London Universities and we are preparing to arrange introductions on their behalf. Professor Karol Sikora of Hammersmith Hospital has been asked to provide an introduction in this country for an oncologist member of the Academy who specialises in breast cancer and the application of Voll electroacupuncture. Assistance has been given for three doctors from the Academy to visit London with their families in January 1995. And, following her meeting with our guests in June, Mo Usher of the Association of Reflexologists has visited the Academy in Moscow and given a presentation and workshop on reflexology.

Russia seeks expert advice on primary care reforms.

Simon House describes the problems and benefits of introducing family style primary medical care into Russia's health care system.

Our NHS is taking on new methods of funding and control, but for generations we have taken for granted general practice. Such a family style of primary medical care is rare in developed countries, which spend much more on hospitals and specialists than general practitioners.

In Russia doctors in training have to specialise from the start, although they can "specialise" in a narrower form of "general medicine". So local doctors are specialists.

In 1978 Michael Ryan¹ (a regular contributor to the BMJ on healthcare in the FSU) saw "a single-entry broad-gauged training for all intending doctors" as unthinkable to the Soviet Union. But, following the Gorbachev "miracle" changes, the FSU seems intent on just such a revision. Now Russians are involved in a project to visit the UK and observe our primary health care system, changes and all.

If their switch to family medicine / general practice is to succeed, then their entire medical specialist education system will need to undergo a fundamental change to a system which is more generalist in its scope. As Dr John Stephen² sees it, a successful switch would have to be very gradual. In time, plenty of doctors in training would need to continue in a broader form of general medicine and qualify as general practitioners.

Growth of Soviet Medicine

The Soviet Union's achievement of a Health Service for the entire population, introduced following the 1917 Revolution, was remarkable indeed. Until then the people's healthcare depended on the *feldschers* - midwives/nurses, not highly trained.

Michael Ryan PhD ¹*The Organisation of Soviet Medical Care* 1978

²Author of *An Analysis of Primary Medical Care 1979* which includes a chapter on the USSR

From 1917 numerically the doctor to population ratio rose to compare with any western country, although not all to the same standards of training. Starting in 1950 the Soviet Union tripled its number of doctors in twenty-four years.

It was the subsequent impoverishment in the eighties which led to the crumbling of a health service which in some ways had been over-providing for its patients, to the extent of excessive check-ups and hospitalisations, at least in rural areas. Not that the patient received all this free. You had to be generous and, even in hospital, tip - or wait. Failure to tip sometimes led to a jab with a blunt needle!

Despite recent setbacks we can only admire the Soviet Union's raising of life expectation over 1916 - 1971 from 30 years to 70. Attention to preventive medicine has played its part. Such success as Russia has had must owe much to its Primary Health Service of which these are the main features:

- Separate adult and paediatric polyclinics and the factory polyclinic which looks after the families of workers, an excellent practice.
- Emergency departments of hospitals
- Rural health units
- Rural hospitals *Feldscher*/midwife posts

An IIHA Consultation

IIHA wishes to share with the Russians in a Consultation towards rebuilding the Russian Primary Health Service on the basis of previous strengths, whilst also attending to weaknesses and needs.

The Consultation will concern itself with patients especially, as well as health workers (doctors, nurses, midwives et al) to find out how their needs are being met; to discover which elements of the Primary Health Service are successful and which are not, so that an appropriate form of primary medical care can be developed, whether generalist or specialist.

We are currently seeking funding for this project which could have wide effects. The global trend in the fifties was away from general practice, but fresh interest has since revived.

Provided Russia can regain her stability, and level of material resourcing, being a nation with vision and will, she could in decades re-establish an appropriate primary medical service for her entire population, one valid as a global model.

Broadening the approach to healthcare

Russians are open to new thinking about health and are particularly interested in what are described as whole person approaches to health, which means the integration of different specialties and skills. In other words, an inter-disciplinary approach.

We are looking for opportunities to help broaden the primary health approach in Russia and the Ukraine where we are developing new partnerships in the Odessa region.

We hope that the most effective of complementary therapies - which are being introduced into our own NHS, especially in the relief of illnesses associated with stress - will be integrated into Russian and Ukrainian mainstream medicine.

We also support community approaches to health such as the *Peckham Experiment*, which goes back to the 1930s and is being revived in Sheffield and other places.

Concentrating on self-help, it aims to meet the totality of needs of families working and playing together in close-knit communities.

Britain is opening up in these ways. A recent article in the *Independent* called *A Common Sense of Community* describes techniques used for over 20 years by a team of professionals to turn Balsall Heath, a derelict inner-city neighbourhood of Birmingham, into a thriving, cared-for and prosperous community.

Serious attention is also being given to nutrition guidance, and doctors are recognising that good health depends more on good housing, education and nutrition than on medicine.

This is why IIHA supports research into the causes of health as well as the causes of disease. The Russians are not slow to appreciate the importance of this philosophy, which focuses on lifestyles and could help to solve many of their present-day problems, which have their origin in ecological degradation and social neglect.

We would like to thank John Stephen and Michael Ryan for all their help in designing our primary healthcare consultation project. We are extremely fortunate in having them as leading members of our team.

IIHA's Reproductive Health Programme



by
Simon
House

An important part of IIHA's Health of Future Generations campaign is our reproductive health programme (RHP) designed to prevent physical and psychological damage to children *before they are conceived.*

Research among mothers and babies by Professor Michael Crawford,¹ in London's East End, reveals levels of alarmingly low birthweight, which are associated with birth defects and varying degrees of ill-health at birth.

The following figures comparing low birthweights in Hackney and Moscow indicate the seriousness of the problem:

Low birthweight children per 1,000 births

Hackney overall	90
Hackney's worst area	140
of which 7 per cent have severe disabilities (mainly cerebral palsy)	

In Moscow a rate of 700 per 1,000 have serious birth defects or are ill at birth. This was recently reported in the *Moscow Medical Gazette*. It is far higher than London's worst area.

RHP aims to provide 2,000 women, who wish to conceive, with special food supplements through the winter shortages. Professor Crawford's research shows that this RHP nutrition programme will substantially reduce the number of children born ill or with serious birth defects.

Parents' smoking and drinking habits are among the main physical causes of damage to these children, as well as pollution in the home and the general environment. But particularly significant is a poor diet. Good nutrition can protect children from damage from these various causes, pollution included

The most important period in determining the health of a baby are the weeks before and immediately following conception. This may come as a surprise, but there is convincing evidence that the outcome of pregnancy is determined by the preconception health of parents and the health of the mother in the early stage of pregnancy when she may not even know she is going to have a child.

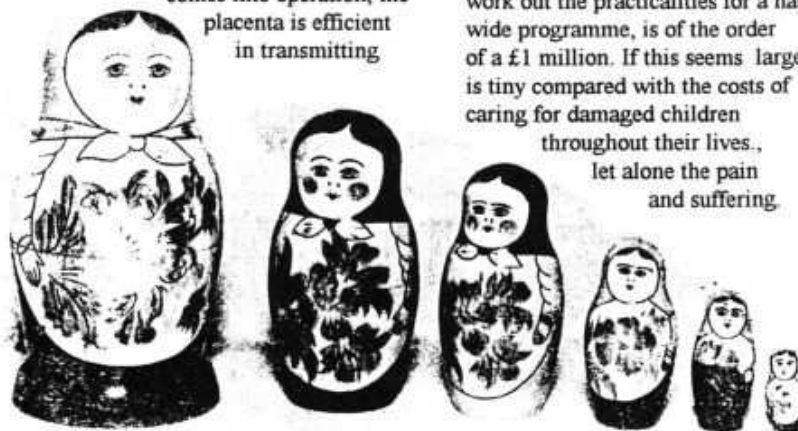
For a sound and healthy child both the egg, and the sperm, *must* not be damaged by lack of essential nutrients. So the necessity for the mother and the father to have had a healthy diet without consuming poisonous substances such as alcohol or nicotine, for some while before conception and certainly not after conception is scarcely surprising.

Once fertilised, the ovum begins growing by cell division and, after a few days when there may be eight cells, they begin differentiating towards forming the various organs of the body.

If the embryo is to retain its potential to become a complete and healthy person, it must have readily available protein and specific vitamins - particularly folic acid - and certain 'trace minerals' must not be absent.

While foundations of the human body are being formed, all the essential nutrients must be present to prevent early cellular damage to the child which could last a lifetime. If development is impaired in these early stages there is no way of correcting it. And the organ most susceptible is the brain.

During this most critical stage of the child's formation there is a further reason why the mother's state of nutrition is so crucial to the embryo. The placenta is not yet formed. Once it comes into operation, the placenta is efficient in transmitting



all the necessary nutrients that are available from the mother's bloodstream into the child's. It even stores nutrients for the child, offsetting fluctuations in the mother's diet.

But until the placenta is formed nutrients have to pass, less efficiently, through fingerlike projections (called chorionic villi) which cling to the lining of the uterus (the endometrium) for dear life! So at this stage the child's present, and future, well-being depends directly on the mother's state of nutrition.

Where nutrition is threatened, IIHA's work to secure good nourishment for mothers-to-be, is absolutely vital in raising sound and healthy children.

Discovery that a period of malnutrition at the time of conception has a greater effect on the outcome of pregnancy than malnutrition which occurs after the early stages of gestation, was made during the war when the Dutch were being starved by the enemy.

Careful statistics were kept at the time, and for many years afterwards. These revealed that when baby girls grew up, they suffered a high incidence of children born ill or with severe birth defects. This again is less surprising if you consider that when a baby girl is born she already has her full complement of eggs for life.

We are currently appealing and applying for funds to mount the programme in an area in the Former Soviet Union to include 2,000 women who are likely to become pregnant. The effectiveness of the programme will be statistically and precisely monitored.

The cost of this crucial stage, to work out the practicalities for a nation wide programme, is of the order of a £1 million. If this seems large, it is tiny compared with the costs of caring for damaged children throughout their lives., let alone the pain and suffering.

¹British Institute of Brain Chemistry and Human Nutrition

To Russia with LOVE

Ben House explains how the idea of helping a handful of children blossomed into a huge life-saving project

Even last April the name cystic fibrosis meant little to me, apart from the fact that it was a rare illness none of whose symptoms I knew. That was before Dorothea Ridgway sat with me and a friend in a Moscow hotel room and gently enlightened us by talking about Tony.

Dorothea told us that she and Roy had had a son, Tony, with CF. When he was born the doctors didn't give him more than five years to live. But he confounded all predictions by going on to lead an extremely full life until he was nearly 30.

Dorothea explained that CF was one of the most common inherited diseases among Caucasian people, affecting almost one newborn child in every 2000.

A misnomer

The name cystic fibrosis is really a misnomer. It would be far more descriptive to call it sticky mucous or *mucoviscidosis* as they do in Russia and other European countries. Both breathing and digestion are severely affected by CF. The two main consequences are that the body's natural digestive juices cannot reach the gut, and the lungs steadily become more and more damaged as a result of recurrent infections by bacteria which thrive in the sticky mucous environment.

Help is just around the corner.

Dorothea said she would like to try and help just a few of the Moscow children suffering from CF. She had already sent a letter to one Russian CF specialist offering help, but he'd reluctantly given up treating CF because he just didn't have access to the necessary enzymes and antibiotics. However, he gave Dorothea the name of another doctor, Professor Nikolai Kapranov, who was still working with CF children. Finally, on the last day of our stay in Moscow - after many phone calls - Dorothea tracked down the elusive professor, to discover to her surprise that the CF centre was not on the other side of town as we had imagined, but was in fact just fifteen minutes walk from our hotel!

First meeting

A rather grim-looking grey concrete hospital wing houses the CF Centre.

Alexander Zhashkov, the father of a little girl with CF, and head of the CF parents association, and Professor Kapranov led us along drab and ill-lit corridors to the wards where they introduced us to the children staying there for treatment. The children engaged our inquiring looks with equal interest and curiosity, and seemed delighted by our meagre presents of sweets and postcards. Their mothers who were staying with them and seemed to work as additional nurses-cum-orderlies, told us how far they had come - the centre serves all of Russia. Some had travelled several thousand miles. There was an air of despondency and resignation among parents and staff.

Bare cupboards

They told us how difficult it was to get medicines for their children, that prescriptions were not worth the paper they were written on as the state chemists were unable to provide the medicines they needed. The parents therefore had to turn to hard currency chemists, where the range of medicines stocked is broader but just as erratic. At these 'chemists', which may be no more than a small table-top stall in a hotel foyer, the medicine is likely to be out of stock or out of date or insufficient for a full course. Furthermore the price is often two or three times that in the West. This can amount to a month's salary for a single course of antibiotics or a few weeks' supply of pancreatic enzyme.

Russian-made enzymes are available but because these are in an uncoated powder

form they are virtually destroyed by the time they reach the right part of the gut. Consequently, the food in a child's meal would be dwarfed by the quantity of enzyme powder necessary to digest it.

All enzymes are not equal

Enzymes like these were commonly used in the West in the 1960s and 70s, but in the 80s a method was developed for enterically coating the enzymes so that instead of a patient having to eat a whole bowlful of powder, just a couple of teaspoonfuls or capsules with each meal is enough for them to digest everything. Additionally, the new enzymes enable children with CF to digest fat, and therefore they no longer have to stick to a strict no-fat diet. A child born with CF in the UK today is now expected to reach their forties; in Moscow they are not expected to live beyond 15.

Having met these children, Dorothea was determined to help some of them. Clearly we could not help all of the 150 diagnosed with CF in Russia, but certainly we could start with two or three.

On returning to England we spoke to Dr Chris Rolles at Southampton General Hospital and told him about the situation in Moscow. He was extremely interested, and said that if we could fund his visit, he would go out there and see what the best approach might be. So, with the support of Dr Caroline Collier of the International Relations Unit of the UK Department of Health, Chris went out to Moscow for four days in August last year when he had the opportunity to meet the staff and build a clearer picture of the CF service in Russia.



But all children should be equal

Dr Chris Rolles returned very excited saying there were definitely ways in which we could help. However, he felt it would not be reasonable to help only two or three children, but we should aim to help all those living within easy reach of Moscow - about 40 or 50! He proposed an approach akin to that of Intermediate Technology. We would introduce a level of care achieving at least 90% of that in the West for no more than 10% of the cost. The aim: to focus primarily on those areas which would most significantly improve the children's health: nutrition and physiotherapy. CF care in the UK being notoriously expensive (around £10,000 or more per child per year), this would still be a fairly expensive project.

Nevertheless, not too deterred, we applied for funding from both the EC and the UK's Know How Fund as well as our Department of Health. The latter was quite willing to fund the necessary airfares for UK medical staff to go over to Moscow and exceptionally a few Russian staff to come here, but it seemed impossible to fund any medicines.

From Moscow to Southampton

The first stage of the project was to invite Professor Kapranov and two of his staff to Britain to meet the Southampton CF team, and to see how children with CF are cared for here. So again with Dr Collier's support, we arranged for the three Russian doctors to come in September. Roy and I met them at Heathrow, and briefly showed them Winchester before delivering them to Chris. Rather than

staying in hotels as most Russian doctors have done in the past, they stayed at the homes of doctors from Southampton, thus allowing them to get to know each other far better. Their ten days here were packed with things to do and people to see. The finale of their stay was a large lively party held at Lena Kukowski's flat at the Barbican, which gave them an opportunity to meet many members of IIHA and the Renaissance Group. Despite its whirlwind, non-stop nature, the doctors' visit was a real success.

While they were here they worked out a project protocol with Chris and his team, with which we supported our applications for funding. However, we found our task a difficult one and our appeals being rejected on the grounds that we were focusing on too obscure an illness. We therefore wrote to all the CF Associations around the world in the hope that at least one country might be able to support the work we were proposing in Russia. They wrote back praising our proposals, but were unable to offer any financial support.

Meanwhile Chris was busily making further preparations for the project. He had gained the support of Bruce Dunkley of the pharmaceutical firm Duphar who promised to provide a year's supply of the enzyme Creon for up to 50 children at below cost price. Though this still meant we would need to raise £6,000 every three months.

Project begins

The project was set to begin in late November 1993. Flights were booked for doctors Priya Ilangovan and Dr Cathy Hill to go and conduct the first clinic where all

the children in the project would be thoroughly examined and given their initial supply of Creon. Only days before we still had not had any promise of money and it seemed that unless we funded the project entirely from our own pockets we would have to drastically scale it down. At the very last moment, however, Chris came up with a generous donation from another trust fund. This generosity should undoubtedly be returned when our income has risen sufficiently.

Humanitarian drug running

Feeling rather like drug smugglers, Chris and I met under cover of darkness in a car park and transferred the four 20kg boxes of Creon from his car to mine. I then covered them with huge labels emblazoned with HUMANITARIAN AID and delivered them to Heathrow for Roy and Dorothea to collect the following morning.

They arrived at Heathrow and met up with Michael Dibdin of IIHA, and Midge Whitelegg, a medical herbalist, who was going to conduct a smaller project using herbal medicines with CF children living far from Moscow. Midge also had with her 40 kilos of herbal tinctures to add to the collection of humanitarian aid boxes which Roy already had piled high on his trolley. They got everything safely through customs here only to be met by a stubborn set of officials in Moscow, who eventually relented in the face of the persistent Russian doctors.

I followed two days later with a video camera lent by Meridian TV, to film Roy's visit and the project's first clinic.

LIFE WITH A RUSSIAN CF FAMILY

TWO DAYS after my arrival in Moscow I was rung by Andre Bushaev, the father of one of the children in the project, telling me he would be collecting me at my hotel the following day. It had been arranged for me to stay with his family for the rest of my visit. I'd been told he was a military man, and I'd built up an image of a stern, rigid character pushing fifty. So with not a little trepidation I awaited his arrival the following morning. When he turned up I was delighted to find he was light-hearted and relaxed and in his early thirties.

He didn't have a car and we had to walk a mile or so through the woods to the metro. As we stomped through the snow, Andre refusing to let me carry my ridiculously heavy pack, we talked non-stop, asking each other questions about where and how we lived. We took the metro and a bus to his home on the Yaroslavsky Highway, N W of Moscow where he lives in a three-roomed flat on the eleventh floor of a tall block of flats. There he introduced me to his 12-year-old

son Kirill who has CF and his three-year-old daughter Dasha. Marina his wife was out at work buying and selling things on the street in the ubiquitous black market.

The children were a little shy at first, but Andre and Kirill were delighted to discover that I had a video camera with me - Andre's dream come true, as it meant he could film his family for the very first time. He immediately set about starting an epic film of our time together. Dasha and Kirill soon lost their shyness in the excitement of film-making.

Marina returned home looking exhausted, having spent all day outside in minus 15C or below. But like the rest of her family she welcomed me with warmth and humour into their home. Marina speaks no English, and my O Level Russian is rudimentary at best, but we still managed somehow to communicate even when Andre was not there to interpret. Marina used to work as a nursery school teacher, but the wages are inadequate even with Andre's salary to keep the family reasonably clothed and fed. To make ends

meet she has to take her chances on the black market, like almost every other family in Russia today.

I slept in the sitting room-cum-bedroom, which Andre and Marina gave up for me. They slept with Dasha. Each evening before supper I would be summoned by Dasha to her room to partake in a tea party with some of her family of toy. I had to answer the toy telephone when she called me, and come up with an understandable reply in Russian to her animated chattering.

When I wasn't engaged in polite telephone "conversation" with Dasha, I was just as often engaged in self-defence practice as Kirill demonstrated on me the latest shin-bruising or gut-busting kick or chop he had learned at karate that week. I used to feel quite safe with him as he took my hand and led me through the rush hour crush on the metro, knowing that any would-be pickpocket or mugger would find themselves floored in seconds by this small young boy.

BEN HOUSE

Success

After the first few months Duphar was so impressed by the project that it generously agreed to provide the Creon free of charge for the rest of the year. Since then the regular clinics have been held and the children are steadily gaining weight and seem to be fighting off infections, with a reduced need for antibiotics. Before the project began, the doctors expected about a dozen children to die each year, and a similar number to be diagnosed with CF. However, none of the children in the project have died and nearly all have shown significant signs of improvement.

IIHA is also working with the CF parents association to show them some of the fundraising techniques used in this country. Alexander Zhashkov and Evgeni Savitsky will hopefully be coming here for ten days in January to attend a fundraising course run by the Directory of Social Change and to visit the CF Trust in Bromley to see how CF organisations in this country operate.

I took part in a children's party to mark the end of the first year of the project (see below). This was kindly sponsored by the Quakers in Moscow. It was the first ever party to be held at the children's hospital which houses the CF Centre - the first of many we hope!

A bad year for the Bushaevs

As you can see from Andre's letter on page 11, the past year has not been so good for him and his family. On returning from holiday they found their front door smashed in and all their valuables stolen. Not long after, their newly-acquired car was stolen though they managed to get it back.

Kirill was found to have the bacteria *pseudomonas* in his lungs, and they still haven't been able to get hold of the most effective antibiotic to treat it. Then to cap it all, two days before I arrived a lorry's trailer slewed into Andre's car while he was queuing for petrol on an icy road. Luckily Andre was unhurt, but as well as all the difficulties of getting compensation from the lorry driver (insurance seems to be out of the question for most Russians), Marina and her friends now have to carry their large heavy bundles of clothes and material by bus and train and then on foot a quarter of a mile to their freezing market pitch every day.

More to buy but more to pay

Things have changed in Russia since I was last there. For example, there seems to be far more fruit on the shelves, though it's

not cheaper. The queues for petrol stretch back sometimes several blocks with prices apparently varying between 10p and £2 per litre, as free-marketeers seek to make a killing out of the shortages, only to find their licences confiscated for taking it too far. There seems to be prosperity for some as they trundle their newly-purchased TVs home on tiny trolleys.

The Southampton team

During the past year several members of the dedicated Southampton team have volunteered in the running of regular Moscow clinics for the children. I went over with four members of the team, who conducted the clinic marking the end of the first year of the CF project. It went very well. Though there were the usual disagreements over certain differences in clinical practice between the British and Russian staff, at the same time I saw a great deal of warmth and humour on both sides. The results of the first year are now being analysed and will no doubt show how worthwhile the project has been.

A brighter future

Things are looking up in terms of medical supplies. Duphar is doubling their donation of enzymes, and Glaxo will provide 150 courses of antibiotics. We have now found an easier way to get medicines over there courtesy of Aeroflot who kindly carry up to 200kg of humanitarian aid free of charge. Now we only have to arrange the paperwork, take the boxes to Heathrow and get them picked up at the other end.

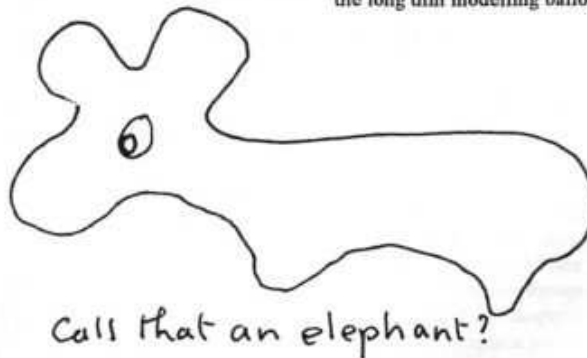
Jelly, cakes, painted faces, ice creams and enzymes

One of the highlights of my visit was the children's party at the CF Centre. Patricia Cockrell invited several Moscow Quakers to entertain the children. Initially the children and parents shyly refused to budge from their seats, but they slowly relaxed as the Quakers played guitars and sang. By the third song nearly everyone was on their feet singing and dancing. I'd gone to Russia laden with party hats, balloons, blowers, sweets and chocolate fingers. We had spent the hour before the party madly wrapping them for pass-the-parcel, only to watch the children delightedly tear off all the layers in a matter of minutes, and soon the air was fit of "parping" party blowers uncoiling to lightly bob the nose of a neighbour.

After a few more games it was time for "tea": coloured plates loaded with everything from marshmallows and smarties to crisps and iced biscuits, topped of course with a small sachet of the enzyme which they need with every meal or snack. By then the children were clamouring to have their faces painted by Judy and Jan from Southampton. Up to that point only one child other than Kirill had volunteered. I had made a so-so attempt to make him look like a ninja turtle, in return he deftly painted me as an amazingly life-like tiger. So lifelike that one little boy who turned round suddenly to face me burst into tears!

Call that an elephant?

Kirill then persuaded me it was time for the long thin modelling balloons which he



Most encouraging of all, it seems that the CF parents association has finally, after several years of hard badgering, had some success in persuading the Moscow region Ministry of Health to provide money for some of the children's prescribed medicines. The parent's task now is to ensure that the relevant medicines are actually registered in Russia by the manufacturer - yet another set of bureaucratic hurdles. Nevertheless this is a huge step forward from last year.

and I had spent the previous day wrestling with to try and shape animals resembling sausage dog, giraffe or swan. We brought them in and soon found ourselves mobbed by children and mothers asking us to make animals for them. The mothers ended up crying with laughter at my attempts at an (hitherto unpractised) elephant.

As the party drew to a close Andre said that he was sure it had really lifted the spirits of everyone who came. Even if it only took their minds off their troubles for a couple of hours, it was well worth it.

ANDRE'S FLAT WAS BURGLED: "NOW I DON'T BELIEVE NOBODY!"

Life in Moscow is becoming very difficult for people like Andre Bushaev, the father of a 13-year boy, Kirill, who suffers from Cystic Fibrosis. . Andre's letter to our treasurer Ben House, reproduced just as he wrote it, gives you a vivid picture of the problems of living in Moscow. There's no insurance except what the Mafia has to offer.

I don't complain, but regret there were not happy and funny moments in our life.

In August 5, when I came back home, I had seen that our flat was burgled. . The criminals-scoundrels took even some children's toys! At once the police explained to us that there will not result!! Now I don't believe nobody!

It disappeared our joint videocassette (no. 1,2,3) from your last visit to Moscow, your present videocassette with comics, the videocassette with the lecture about CF. Also it stole the documents myself, the keys of the car (!), TV, videorecorder, audioapparatus, photocameras, the clothes and many-many other things.

Then, in September 1 - in the first school day in Russia, our car was burgled too(!!)

I and Marina are going to the black market to sell things very often . I must find supplementary job, but it's very difficult. This is our life.

Thanks to you and Roy for your invitation to England. Of course, if there's opportunity, I and Kirill would be going with pleasure to Southampton hospital, but I need very much an official invitation for me and Kirill - better of all from the medical hospital or you can write the aim of our visit - for the treatment of my son.



Kirill
and his
sister
Dasha

It's very important for me. I think that you, Ben, understand me.

Some words about our family. Dasha began to visit the nursery school. She is very pleased. Kirill grown up very much during the summer, but after his return to Moscow from the country Kirill began to cough again - Moscow's ecology!

Dr C. Rolles look at Kirill. He decided to give antibiotics for him. Ben, we need special vitamins: A, E, D. There is no such vitamins in Moscow.

O, Ben, if it's possible, I want to ask you: please record 3(three) our videocassettes of your last visit for me! Such videocassettes is a grate memory for us. Thank you! And certainly bring your videocamera for your 2nd visit to Moscow! I'll meet you in airport and then we'll go to my house together by my old car "Moscvich". Please call me and tell me about your number of your flight, date, time.

We'll glad to see you in Moscow, Better, if you'll come Moscow with Kei.

See you in nearest time. A best biggest regards to Kei, Dorothea, your further, mother.

Successes to you! By-By!

Andrei, Marina and my dear children

P.S. Kirill from Sept 27 in hospital



More things in heaven and earth

Roy Ridgway visits Troisk where top Russian scientists are doing some research into the nature of "subtle energies".

We were expecting a car to call at 9.30 am to take us a few kilometers up the road from our hotel to the Institute of Terrestrial Magnetism in the academy town of Troisk, south-west of Moscow.

There, at this prestigious Russian Academy of Sciences establishment, where they discuss matters way above our heads, we were going to hear about the effects of solar activities on people's health and about how IHA could help in promoting the work of the Institute.

The institute was particularly proud of a magnetometer they had developed for registering magnetic storms. Magnetometer readings are given regularly with the weather forecast on Moscow radio. So why not in Britain? A serious storm can cause desynchronisation (with symptoms such as headaches and problems of co-ordination) leading to road accidents, and could also interfere with electrical power. One such storm put out all the lights of Quebec a few years ago.

Waiting for the bus

We waited and waited. I didn't mind. In Russia one gets used to waiting for as much as an hour or more because of the poor state of the roads and of the vehicles that drive along them. And after all, when we sat waiting in the foyer of our hotel, it was the coldest November day since 1940! In Britain in such conditions we couldn't have got the car out of the garage, let alone onto the road. Just imagine the chaos in London on the coldest day in over fifty years!

This waiting is normal," I said to David, who had his nose in a book called *Dirty Medicine*. "Cars are clapped out! There's no petrol. Windscreen wipers are stolen and sold on the Black Market, and anyway they're no use when ice forms on the inside windows and you have to keep scraping it away as best you can. And drivers won't work for less than a particle physicist gets paid!"

I rang the office of Professor Victor Nikolaevich Oraevsky, the director of the Institute. Irena Veronina, our St Petersburg representative, who had organised the meeting, answered.

"What happened?" she asked.

"I was about to ask you the same question," I said.

"Probably the bus broke down. We'll send a car."

To pass the time, I phoned Professor Vladimir Shinkarenko, Secretary of the Health in the Workplace Programme Committee, to arrange a meeting later in the week.

He asked the same question as Irena: "What happened? We were waiting for you."

I told him I didn't know of any arrangement to meet. No, he agreed, there hadn't been, but didn't we arrive yesterday?

He'd assumed that his office would have been our first port of call and that we'd tried but failed to make contact. It's like that in Russia. There's a breakdown in communications. People don't pass on messages. Fax machines aren't switched on or run out of paper. Telephone lines are jammed. Letters are not delivered. Someone recently found several bags of mail in a St Petersburg canal.

A very senior scientist

Just after I put the phone down, I noticed an elderly man bearing down on me. He wore a thick polo-neck pullover, an anorak and a woolly hat pulled down over his ears.

"I've come with bus," he said, a broad smile spreading over his face. "Sorry we late. Clutch broken. By the way, I not driver. I Sasha - very senior scientist."

Sasha was a redundant physicist who had studied some abstruse subject which was of no use in a market economy. But he knew some English and earned a few roubles as an interpreter.

He didn't stop talking all the way to the Institute. Recently he'd met his sister for the first time in thirty years. She lived in Paris, but he couldn't afford to go there and was too proud to accept her offer to pay his fare; so the mountain had to come to Mohammed.

Where did he learn his English? I asked.

"Voice of America," he said. He'd listened to the American version of the news through all the years of the Cold War. He was grateful to the Americans and was interested in all that was going on in the West, but had no desire to leave Russia.

"Things are pretty awful here. But what's a few years of history!" he said. "The thing is, the Russian people never change. It's the same country as Dostoevsky's, Pushkin's, Tchaikovsky's..."

"And Gorbachev's," I added.

"No Gorbachev," he said, with a disdainful wave of the hand. "Politicians no good!"

When we arrived at the Institute of Terrestrial Magnetism we were ushered into the

director's office where we sat round a board-room style table with Professor Oraevsky and a number of distinguished scientists, including Professor Valentine Makarov of the Pulkova Observatory, St Petersburg; Professor Rapaport of the Sechenov Medical Academy; Professor Schnol of the Institute of Biochemistry and Professor Sufkina of the Institute of Paediatrics.

It is quite remarkable how accessible the high and mighty are in Russia to everyone, no matter who they are, even a humble medical journalist such as myself. This is partly the result of the communist egalitarian philosophy, but also because of the need to raise funds for research, with everyone from the West perceived as a potential source of hard currency.

Our party consisted of David Lorimer, director of the Scientific and Medical Network and a member of the IIHA Council, Dr David Spiro, a London GP who has been a keen supporter of IIHA since its foundation, Jane McWhirter, director of the All Hallows Centre for Complementary Therapies in the City of London, Michael Dibdin, a member of IIHA's Business Management Advisory Committee and myself.

Nobody knows nothing. Cause-and-effect chains are impossible to sort out. Unintended consequences of any action always far outnumber intended consequences. Today's truism is tomorrow's embarrassing memory. Given all that, do something. Pondering whatever for another two hours (or two months) won't help much.

TOM PETERS

All the scientists round the table were members of the Sun-Earth-Humanity Association, a research body interested in solar activities and their effect on health and on climatic conditions and communication systems on earth.

They are interested in working with us in the application of non-drug therapies in the prevention and treatment of heart disease at the Cardiological Centre in Kislovodsk, near the Black Sea, in the prevention and treatment of jet lag (chronomedicine) and in the dissemination of information concerning their work.

The Russians are proud of their scientific achievements and are the most rigorous of researchers. But they are open-minded and, unlike many in the West, do not scoff at the theories of non-conventional therapists merely because they cannot be explained in conventional scientific terms. One of the Institute's departments in Troisk

is investigating what in the East are known as "subtle energies." At present they are concentrating on dowsing.

"No-one knows what is happening when a dowsing rod starts twitching," said Sasha, the senior scientist. "But something is happening and we mean to find out what it is."

They were interested in the Scientific and Medical Network's aim to explore concepts that go beyond generally accepted theories and they approved of the quotation from Niels Bohr on the front of the Network pamphlet: "We must continually count on the appearance of new facts, the inclusion of which within the compass of our earlier experiences may require a revision of our fundamental concepts."

David had no difficulty in enrolling Victor Oraevsky as a member of the Network. In fact there are now lively branches of the Network in Moscow and St Petersburg.

An agreement was signed between Sun-Earth-Humanity, the Scientific and Medical Network and All Hallows House to work together in the various areas of interest mentioned above, including the marketing of a magnetometer, which measures the amplitude of magnetic storms and has various applications including diagnosis in post-operative trauma where patients are sensitive to electro-magnetic disturbances.

Country of believers

It always puzzles me why I keep going back to Russia. What is it that draws me? What is this love affair I have with the country? Certainly, I don't like the present squalid conditions, with all the violence erupting in the streets, the Black Market, the poverty, the homelessness, crumbling buildings and so on. But in spite of all this, I feel strangely at home in Moscow. Most people I have met, even in the Cold War, have been warm-hearted, extremely generous, sharing what little they've got with their guests. They are a great people. They go on believing that one day clouds will break, as they surely must. Even after seventy years of unmitigated horror!

Some words by Guardian journalist

Julian Evans express my own feelings:

Muscovites are solid people, but what they lack in lightness they can make up for in indomitable warmth. Bad living conditions have made them more alive, not less; Russia's seemingly infinite borders incite a search for inner freedom. These are superficial observations. The truth, perhaps, is as the poet Tyutchev described it 125 years ago about Russia as a whole: Moscow isn't open to reason, it's a place in which you have to believe.

That's absolutely right!

THE PLIGHT OF THE RUSSIAN CHILDREN'S HOME

Lena Hyltoft, a student of Russian studies, sums up "a year of happiness and sadness" spent helping out in Moscow Children's Home No. 12.

As a student of Russian Studies at the University of London, I had the opportunity to attend a course for a year at Moscow State University. As my academic specialization is in the area of economics and social policy I was interested in the possible consequences of economic decline on the support system of social institutions such as children's homes in Russia.

Before going to Moscow I had followed media coverage in the Russian press about the plight of the increasing number of children being left in homes unwanted either because of their nationality, mental or physical handicaps. At this time a foreign adoption programme had been initiated and many children's homes were trying to find suitable parents in the West, predominantly families in America for children who otherwise had no prospects of being adopted domestically.

Home dependent on foreign aid

In October 1992 I started working at Moscow Children's Home No. 12 (which is a home caring for children with special needs from the ages of 0-5 years) teaching English to a group of 3-5 year old children who were awaiting adoption to American families.

Being part of the team at the home, I gained valuable insight into how the home was run in the midst of this very difficult time of economic transition. The repercussions from the economic turmoil in the country have particularly affected the area of institutional child care, and through the last three years the children's home had become increasingly dependent on foreign aid. However, foreign aid has been very inconsistent, and the home often relies on the foreign adoptive

parents to make donations when they arrive to collect their adoptive child.

Children in institutional care in Russia do not have a balanced diet, and the diet at the home where I worked improved only sporadically due to Western aid efforts. Many of the American families, who adopted children from home no.12 found that their children were in very poor health due to insufficient nutrition and vitamins as well as suffering from various infections. Infections were very common in the home, but improving hygiene and sanitation is very difficult without the basic materials, although this would greatly improve the welfare of the children.

Lack of teaching aids

At children's home no. 12 there was a complete lack of teaching aids and toys in the special needs area. The children had no access to crayons, pencils, drawing materials and books, so that they had no possibility of developing their motor skills. The absence of stimulation severely stalls their development.

Weakened support systems

The staff tried to be innovative in their approaches, and lamented that the lack of educational aids and facilities caused an enormous imposition on the children, and this in their most formative years. Only very few of them will be adopted by Western families and receive the attention, special tuition and health care that is so vital to their development.

The support systems for social institutions in Russia have been weakened due to the imminent breakdown of the economy. It is difficult to predict when Russia will make a full recovery to stable economic times, but meanwhile it is important to give orphanages like Moscow children's home no. 12 a lifeline to ensure provisions are made for these children with special needs. They have not only been abandoned by their own parents but are also suffering the unfortunate fate of having been born into a time and in a country where dramatic systemic change is taking place, resulting in a scenario where funding previously allocated to social institutions like orphanages is simply not available any more.

A NEW PLACE FOR THE MENTALLY DIFFERENT

Roy Ridgway meets Yuri and his daughter Claudia who has Downs Syndrome

I met Yuri and his pretty little three-year-old daughter Claudia outside the *Dom Tourista* just as I was about to try to squeeze into the front passenger seat of Andre's small car to dash off to do some shopping before going to the airport. But Andre said, "There's someone to see you." I wasn't surprised for the simple reason that nothing ever works out according to plan in Moscow. Always what actually happens is much more interesting than any plan.

Andre lit up a cigarette as he introduced me to Yuri and Claudia.

"Zdrasvidye!" (Hello!) I said to Yuri. And to Claudia, "Preevyet!" (Hi!) I'm beginning to build up a useful vocabulary of essential words and phrases such as "*Ya loobloo va*" ("I love you). *Loobloo* (love) is one of those essential words in everyday use in Moscow. Love is all they've plenty of, baby! Maybe all they need.

Yuri had a letter for me explaining the problems of looking after Claudia, who is a Down's Syndrome girl. In Russia such children are usually sent to institutions. They are rarely kept at home.

"She's a problem," said Yuri. He and his wife Olga love the little blue-eyed girl and would never part with her. But Yuri earns the equivalent of about \$30 a month. They have two other children who are students at Moscow University and Olga can't help with the finances as most wives do she has to stay at home to look after Claudia. Their neighbours, Irena and Victor, who are themselves the parents of a cystic fibrosis boy, help out with gifts of money, clothes and food, and it was Irena who suggested that Yuri should come and see me.

Yuri's letter said that Claudia had been given a course of "fetal tissue transplants" at a cost of \$600. I am not sure how this money was raised but probably it had been saved by

parents, grandparents and other relations and friends.

Yuri mentioned other treatments: "psycho-stimulants", vasodilators and multivitamins. The sad thing is that there is no evidence that any of these treatments are of any use, apart perhaps from the multivitamins which would help the child if she or he was on the normal Russian diet which is lacking in adequate quantities of fresh vegetables and fruit.

Emotionally responsive

From what the father says the girl is happy and emotionally responsive, playing with dolls, toys, lego, and reacting lovingly to her parents. She walks confidently without assistance,

looks at picture books and television and seems to be capable of living a worthwhile and happy life, at least in the bosom of her own family. She is mentally different, of course, and because of this she must be counted as one of the outcasts of our time. To be accepted in 20th century society you must be capable of passing exams, which means thinking in little boxes, in a disciplined way. Knowledge based on emotional experience and communicated in emotional language counts for very little.

Claudia's main problem seems to be lack of social support except from her own family, friends and neighbours. There are no daycare centres or special schools for such

children in Moscow. The good news is that the Down's Syndrome (DS) Association has opened a Moscow Centre to organise immediate comprehensive assistance to DS children and their parents. One of their projects is called *We and the Mentally Different. The 21st Century is a New Place for the Mentally Different in our World.*

I'm glad I met Yuri and Claudia. I've been able to pass on a very important telephone number and an address to them, which could change Claudia's life: For others who might be interested in the telephone number of the Downs Syndrome Association in Moscow it is: **095 925 64 76.**

Address: 133 Myasnitskaya St. Flat 3,
Ya loobloo Claudia.

WOULD YOU LIKE TO JOIN Iiha's VOLUNTARY TEAM?

If so, please drop us a line. We'd like to know your skills or hobbies. Are you a dab hand at photography? Can you sketch, write copy for leaflets, ads etc? Which project interests you most?

- If you live in London, can you offer hospitality to a distinguished academician, head of the Paediatric Department, Pirogov Medical Institute, Odessa, on January 16th for a week?
- Could you act as interpreter when our Russian and Ukrainian friends are visiting London, Winchester or Southampton?
- We need an experienced fund raiser willing to work regularly on a commission basis.
- Could you help organise social events, seminars or conferences?
- Are you interested in developing and running projects?
- Would you be interested in helping the Russian children's home? There are many different skills needed from play therapy and toy-making to helping build a playground.

WE'D BE DELIGHTED TO HEAR FROM YOU. DO WRITE OR CALL OR LEAVE AN ANSWERPHONE MESSAGE.

FINALLY contributions to this newsletter, including articles, letters, brickbats, bouquets, cartoons and photos would be most welcome.

INTERNATIONAL INTEGRATED HEALTH ASSOCIATION

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Registered Charity No 1014734. E C Central Register PHARE/TACIS No UNK 9500

HEALTH IN THE WORKPLACE

This international conference was initiated by IIHA and took place at the President Hotel, Moscow in May, 1994. Apart from IIHA, the organisers included the Moscow Government Centre for Health Problems and the Liverpool John Moores University.

It is planned to make this an annual event with Liverpool being chosen as the venue of the next conference in May, 1995. Preliminary discussions about what shape the conference will take are to be held at the Liverpool John Moores University in December.

The idea of the conference followed discussions between the late Professor Vladimir Ilyin, then head of the Department for Non-Drug Therapies at the Sechenov Medical Academy, and Roy Ridgway in 1990. They shared a belief in an holistic approach to health, which would mean, among other things, paying close attention to occupational and environmental health issues. They planned a series of events, of which Health in the Workplace was one.

IIHA arranged for Professor Ilyin and his colleagues, including Professor Alexander Razumov, director of the Moscow Centre for Health Problems, to visit Liverpool Polytechnic (now John Moores University) for discussions on their participation in the conference, which then began to take shape with Dr Jane Springett, of the Health Sciences Department and now a member of IIHA's Council, playing a prominent part.

Originally the aim was to exchange experiences and ideas on the latest theories and practices concerning health in the workplace, but it broadened out to include a wide range of subjects many of them relating to Russia's present appalling health problems.

A message from President Boris Yeltsin stressed the need to find new and more effective approaches to

public health which he suggested should involve businessmen as well as scientists and physicians. "It is important," said Yeltsin, "to develop international co-operation and draw on international experience."

Professor Alexander Razumov talked of Russia's "worsening gene pool" which he said was responsible for an unacceptably high rate of illness in newborns. He described the main causes of ill-health in the following order of incidence:

1. lifestyle: 50-55 per cent.
2. environment: 20-25 per cent
3. genetic factors: 15-20 per cent.
4. aetrogenic (i.e. caused by the treatment itself: in other words by doctors and hospitals) 10-15 per cent.

Professor Razumov stressed the need for preventive medicine directed at early recognition of pre-clinical conditions.

Professor Mikhael Palstev, Rector of the Sechenov Medical Academy, gave a presentation mainly devoted to new trends in medical education and the need for expert advice in training family doctors and specialists in health management. Professor Palstev said that help from the international community was urgently needed in planning educational courses in these new disciplines.

A number of speakers concentrated on women's health which is a matter of grave concern in Russia today. Dr O Frioiva, of the Russian Academy of Medical Sciences Research Centre for Gynaecology and Obstetrics, presented a paper on safe motherhood. "A combination of the right medical conditions," she said, "with favourable socio-economic factors produces healthy children."

She went on to describe the deteriorating reproductive health of Russian women, which has resulted in 65 per cent of pregnancies being terminated. She gave other alarming statistics - eg maternal mortality which stands at 50 per 100,000 live births. Many children, she said, died in the first year of life, and of these more than 65 per cent die at birth.

New placental diagnostic technique

A new placental diagnostic technique, developed after seven years research at the Central Children's Hospital in Novgorod, Russia, is saving the lives of many low birthweight children.

Dr Mikhail Ofengame, director of the Placenta Laboratory in the hospital's Department of Pathomorphology, freezes the afterbirth within 48 hours of the delivery of a child and subjects the placenta, membranes and umbilical cord to microscopic examination.

In this way he is able to identify probable infections and hypoxia (decreased supply of oxygen) in newborn infants.

Babies, who are normally sent home soon after birth, are kept in hospital for further treatment if there is any suggestion of infection, or reduced oxygen supply. The placenta of virtually every delivery in the children's hospital is examined in this way. Dr Ofengame claims that infant mortality in Novgorod went down from 20.6 to 15.1 per cent between 1986 and 1993 as the result of his new technique.

The Children's Hospital is now conducting clinical trials of a device developed by the American fetal behaviour specialist Dr Brent Logan, who claims that through sonic stimulation he is able to invigorate placental walls and thereby increase the baby's absorption of nutrients from the mother. There is a great deal of controversy over Dr Logan's device which is marketed as Babyplus, but Russian research may help to prove all that Dr Logan claims for his device which he says he has tested on 10,000 children with excellent results. IIHA has

been invited to collaborate with Dr Logan and Dr Ofengame in incorporating their work in our Health of Future Generations Campaign.

Free subscriptions

In response to a request by IIHA, Dr Richard Smith, editor of the *British Medical Journal*, is trying to arrange for IIHA's Odessa colleague Professor Reznik, head of the Paediatric Department of the Pirogov Medical Institute, to receive free subscriptions to the *Archives of Disease in Childhood*, one of the world's major paediatric journals, and the *BMJ*.