

INTEGRATED HEALTH CARE

Newsletter of International Integrated Health Association (IIHA)

Registered charity no. 1014734 3 The Square, Winchester SO23 9ES Tel/Fax 01962 865 858

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SUCCESS STORY

It is now two years since we launched the IIHA Southampton/Moscow Cystic Fibrosis Project, which has been very successful and has developed into a model for child health care in Moscow's Republican Children's Hospital. The unco-ordinated hospital service for CF in Moscow is now an organised, co-ordinated service with regular note-keeping, good documentation and regular outpatient clinics even for children who are relatively well.

Other chronic illnesses

In Moscow our work is expanding to include help for other chronic illnesses including diabetes and allergic conditions such as asthma. We have also established a partnership with the Society for Children with Cardio-Vascular Diseases (see page 13). Our work is developing more into a social programme and is less concerned with medical twinning, valuable though this is, especially from the point of view of the Russian doctors' morale, which is so low at present. But though medically things are going well, socially and psychologically the overall care of children with chronic illnesses is disorganised and somewhat haphazard. So we are now concentrating our efforts on the social and psychological needs of children and their families.

The Moscow team

Among those who are working with us are Peter Kent, head of the UK CF Trust's Family and Adult Support Services, psychotherapist Susan Van Dias (well-known for her work at Moscow's Tushinskaya Children's Hospital) Patricia Cockrell, head of the Moscow branch of Quaker Peace and Service and the Catholic Apostolic Office in Moscow.

In November Judi Maddison, CF specialist nurse at Southampton General Hospital is to undertake an extensive fact finding programme specifically directed toward non-hospital based service and support for children.

Meanwhile, in Winchester we are working seven days a week to keep up the momentum. IIHA's work has almost doubled since the publication of our summer Newsletter, but we still rely a great deal on voluntary work and the dedication of our doctors in London, Southampton, Moscow and Odessa. Our need now is for more substantial core funding to allow us to employ additional executive staff on a permanent basis, so we are appealing to you, our readers, to help us in any way you can. What we are doing in Russia and the Ukraine is not only creating new models for health care, which will benefit other parts of the world, but is also creating a model for peace-building, which is essentially concerned with our way of living in the world: not preaching, but demonstrating how diverse groups can work together in harmony to help the disadvantaged. A good example of unity in diversity.

EUROPEAN COMMISSION CO-FINANCES IIHA'S CHILD HEALTH CARE PROJECT

The European Commission Phare/Tacis LIEN Programme, which was set up to help disadvantaged groups in Russia and the new republics, has selected IIHA's Care of Children with Chronic Illnesses and their Families in the Ukraine for co-funding. Other funders include Charity Know How, a Foreign and Commonwealth Office initiative, which has supported IIHA since it was established in 1992, and the UK Department of Health, which financed a feasibility study in Odessa.

The groups initially targeted in the IIHA partnership project are children suffering from cystic fibrosis, a most distressing genetic disorder, the main features of which are: (1) sticky mucus which clogs airways and leads to lung infection; and (2) clogging of the pancreatic duct, leading to a deficiency of digestive enzymes and malnutrition.

The IIHA project will introduce modern treatments which will improve the quality of life of these children. IIHA will also help to establish national and local support groups and organise the necessary training for them to deal with health and social problems.

Partners in the project are the Royal Brompton Hospital in London, the Odessa CF Trust and the Odessa University Hospital (Pirogov).

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UKRAINE BENEFITS FROM SUCCESS OF MOSCOW CF PROJECT

The European Commission Phare/Tacis Lien Programme selection of IIHA's project for co-funding is the result of much hard work over the past two years in Moscow and more recently in Odessa. The Southampton/Moscow cystic fibrosis project has become a model for child health care, and lessons learnt there will be applied to our work in Odessa.

IIHA and the Royal Brompton Hospital decided to go ahead with the Odessa project, if funding could be found, after a fact finding mission by consultant respiratory paediatrician Dr Mark Rosenthal and executive staff of IIHA. Since then there have been two medical exchanges, two consultants from the Odessa University Hospital (the Pirogov) coming to London for training at the Royal Brompton Hospital and two consultants going to Odessa for further training of doctors there, including training in physiotherapy, which is so essential in the treatment of cystic fibrosis.

The Royal Brompton Hospital could not be a better choice for twinning with the Odessa hospital, which is the main Ukrainian centre for CF treatment. The Brompton is the largest cystic fibrosis centre in Europe. It looks after 350 children and 750 adults and is the only hospital in the UK catering exclusively for heart and lung disease in adults and children.

The Ukraine CF project was launched in April this year with a visit to Odessa by Dr Mark Rosenthal, Paediatric respiratory Research Fellow Dr Jane Davies, and Senior Paediatric Physiotherapist Gill Phillips. Nearly hundred children from all over the Ukraine, some travelling over two and a half thousand kilometres, came to the University Hospital for an assessment of their growth, lung function and nutritional status. However, the main purpose of the doctors' visit was to meet the families and encourage them to develop an esprit de corps rather than continue to suffer their previous isolated state. The parents were also taught the latest methods of physiotherapy.

At that time we had very little in the way of medicines, but the Lien Programme grant will enable us to purchase life-saving pancreatic enzymes which all the children need and to develop family support groups.

After his visit Mark Rosenthal commented: "This population of children with CF represents probably the last untreated group of Caucasian children with CF. The opportunity to observe the benefits of modern management, which would be impossible in any Western European country, is of tremendous value."

Dr Mark Rosenthal examines a child in the hospital lecture hall. He was the only doctor without a white coat and his sensitive style of teaching impressed everyone.



A WEEK IN MOSCOW

IIHA visits Moscow to help set up CF family support services. Roy Ridgway reports.

I took a thick woollen Crombie with me, but it wasn't needed. Everyone in Moscow was talking about the "unusual" weather. It had been the warmest, driest summer on record, affecting people's health, especially old people who had respiratory problems because of the heat. And in the first week in October when I was there it was still sunny.

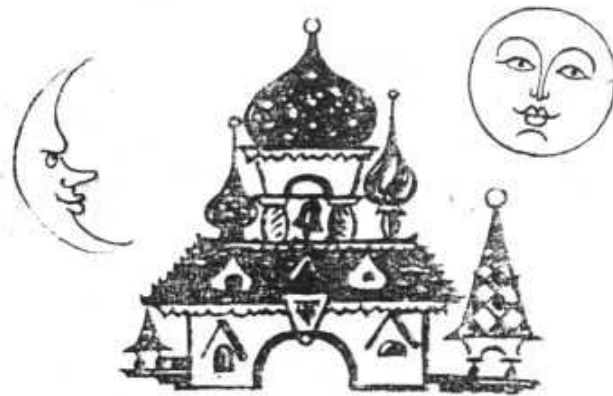
It was a week of contrasts - sometimes enjoyable and stimulating, at other times depressing, disturbing and frustrating. Nothing new about this, of course. It's always the same every time I visit Moscow, and the people don't change much either: they are still struggling to make ends meet, they have no faith in the future. On the other hand, I've always found them warm-hearted, welcoming and generous and those we know and work with believe that it's only their association with us that gives them any hope.

No doubt the visit was a thrill for Peter Kent, the head of the Family and Adult Support Services of the CF Trust in the U.K. who came with me. But it must have been a shock, with all the dirt and litter, the beggars, the street children, the crumbling buildings, the grey, cheerless corridors and wards of hospitals.

On the day we arrived there were reports that the economy was settling down with inflation now around 5 per cent. There is a lot of construction work going on including the rebuilding of the Moscow cathedral, which Stalin blew up, the construction of a huge underground shopping complex in the middle of Moscow, and improvements to the ring road, which has always been known as "the killer road." There are many more restaurants and road-side kiosks and at night Moscow is bathed in a blaze of light and is beginning to look like any other European city, with many pleasure seeking people milling around in the centre, most of them looking much better off than they were a few years ago.

But in spite of this, there is still a lot of poverty - the gap between rich and poor goes on widening - with scientists and doctors complaining that the government finds the money to pay for so much construction work while they receive very little pay themselves or no pay at all for months on end. Professor Zilov of the prestigious First Medical Academy (I.M. Sechenov) and his deputy, Dr Ludmilla Kudaeva, said they hadn't received any pay since August. A man on the metro, an engineer by profession, told Ludmilla that he received \$50 a month and out of this had to pay \$30 in rent. Many professionals, including doctors, are in a similar position.

Most people are extremely worried about the elections to the Douma in December, fearing the worst, with

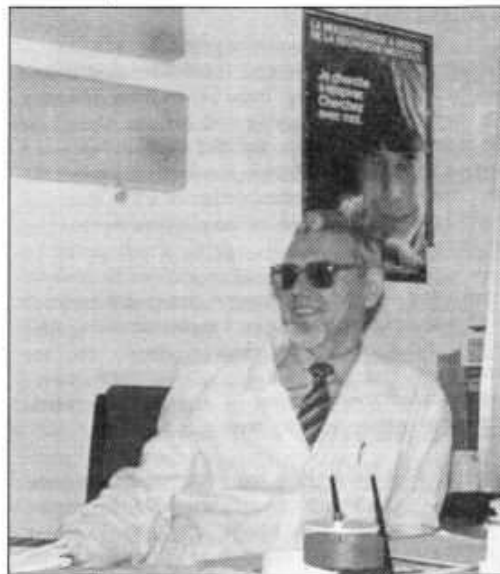


hard-liners once again in power. People are just as miserable and despondent as ever. But it would be surprising if they felt otherwise. The Russians have endured 70 years of revolution, war and Stalinst terror and their history, going back centuries, is one of repression. This has, I am sure, made them very suspicious of any promises of better times to come. They just don't believe it.

Meeting with Professor Kapranov's team

Professor Nikolai Kapranov, the head of the CF Department at the Republican Children's Hospital, and his team spoke of their hopes and aspirations. "I would like our CF project to continue," he said. "Before it began in 1993 we were babes. Now we know a lot more, but we can still make mistakes and desperately need the support of the IIHA and Southampton - not only because we value your expertise, but because the situation in Russia is so unstable. Our patients could suffer as the result of political decisions. All treatment could be disbanded. Collaboration with you does a lot for our self-confidence. It's the only stable part of our lives."

"Before the CF project began we were babes," said Professor Nikolai Kapranov



We talked about the future. I put forward the suggestion that a seminar could be held for polyclinic doctors about CF diagnosis and the dissemination of other information that would strengthen ties between hospital doctors, families and paediatric therapists. There is a great deal of interest in family medicine which is practically unknown in Russia.

The seminar could be a useful first step in the reform of primary health care in Moscow. IHA is organising a presentation on primary health care by Western experts to the Family Medicine Department of the First Medical Academy (I.M. Sechenov), in January, 1996. The seminar at the Republican Children's Hospital could take place at the same time.

Pancreatic enzymes

The question of future supplies of pancreatic enzymes came up at almost every meeting we attended. Nikolai said that they had put in a request to the Ministry of Health about the provision of enzymes, but nobody believes that anything will come of this.

It's not certain who will be the Minister of Health or if the present government health department staff will be retained after the December elections. So everything is in the melting pot.

Two main pharmaceutical firms are competing for the market for pancreatic enzymes - namely, Solvay/Duphar and Knoll. Of the two, Knoll is the more aggressive and has sided more with the parents's charity than the doctors. Peter Kent describes their strategy as a frontier approach which might not "sit comfortably with Western European methods, but will be acceptable, and work, in Russia."

Parents Meeting

About fifty parents came to this meeting held in the Republican Children's Hospital. Most of them looked pretty grim at first and I don't think they expected anything much to come out of the meeting. We wanted to talk to the parents on their own so the doctors agreed to leave us alone.

Nikolai Kapranov introduced Peter Kent and myself and then left the meeting. Irene Myamikova (a mother who had visited Southampton with her son Alexei) did the interpreting for Peter and the Quaker Peace and Service representative Patricia Cockrell interpreted for me. Nina (who is the grandmother of a CF child and works in the hospital) was on the platform representing the doctors.

I spoke first about the meaning of "integrated health" - integrating different disciplines, I explained, integrating groups disadvantaged by chronic illness into the community, and integrating mind/body/spirit/environment - treating the whole person, not merely repairing parts.

I also spoke briefly about the European Commission LIEN programme, which is aimed at developing sustainable social and health programmes where infrastructures and services are weak. In keeping with

this programme, IHA hoped to help in the establishment of family support services. We are hoping to obtain a substantial grant for this purpose.

Peter then took over and said that he was there to ask questions about how he could help, not to impose his ideas on them. The parents were all very depressed and angry about the present political situation. Peter felt at one point that he was "being got at." I felt helpless as I looked round at a sea of faces that didn't seem at all friendly at first. None of them seemed to understand how we could help or why we were there.



They said such things as:

- We need practical help because many women can't work. The woman speaking said she'd had an offer of money from Italy, but none had arrived.
- It's not so much money we need. Children need enzymes and antibiotics.
- It's people outside Moscow who have major problems. Drugs are not always free but can only be obtained with cash. There are local problems which are not always present at a Russian level.
- We can only count on ourselves and charity. The government is no help. Until we get someone like Margaret Thatcher nothing will change.
- Several people said the situation was desperate.
- It's not psychological support that is needed. It's a question of survival.
- Woman from Yaroslavl: We have a small centre for about ten children. We have a problem because the State does not think CF children are disabled in any way. They have arms and legs and do not look ill, and when we tell doctors about their digestive problems, they don't understand: they just refer them to a gastro-enterologist. The majority of people don't understand what the problems are. They don't understand the children have special needs. The polyclinic doctors don't know how to tell if any problems are starting and so treatment is often delayed and minor problems become severe. Outside Moscow the problems are much greater and very few of the doctors know how to tackle CF.
- Another woman whose child of two to three months, who failed to was taken to the Polyclinic where they diagnosed bronchitis. This woman from Vladimir said she now has no problem in obtaining Creon, but she knows of a lot of people who don't have Creon and take old forms of pancreatic enzymes.

At one point the meeting became so negative and despairing that both Peter and I said that we had nothing to gain by coming to Moscow and if they didn't think we could help we wouldn't come again. There was then a sudden change of mood and cries of "Niet! Niet! We need your help."

After having been greeted with total silence following my opening remarks I was cheered by everyone present when I wound up the meeting. They had all agreed to the democratic election of a family and adult support group, which would represent parents, doctors, the Catholics, who are providing funds to build a new CF Centre in Moscow. It was also suggested that someone should be appointed solely for his/her counselling or other skills, who was not weighed down by the illness of a child in the family. We felt that parents were not thinking clearly because they were so worried about their children as well as the political and economic situation.

Research and the way forward

It is a common complaint that although medical research, which is concentrated in Moscow, is of a very high standard, it has very little impact on the development of diagnostic and treatment methods. Another complaint is that the polyclinics employ doctors with the lowest standard of training, and in the case of CF and other chronic illnesses are of little help to families. (See Stewart Britten: *Russia/CIS Improving Health Care Medical Technology International, 1995/6*)

Obviously, research is benefiting some pharmaceutical companies and the medical elite who are engaged in research. I don't think the patients and their families benefit very much, and there is a desperate need for a programme, such as the European Commission LIEN Programme, which seeks to help groups in areas where social and health infrastructures are weak (See LIEN (Link Inter European NGOs) Programme. PHARE and TACIS 1995).

It seems to me that all research should be aimed at improving the health of patients and should be followed by guidelines to patients and doctors about the application of research findings. These should take into account local circumstances. Also, all treatments should be evidence-based and cost-effective. Otherwise, patients are going to feel that they are just guinea pigs for the researchers.

European Commission LIEN Programme

Our visit was the first step in implementing a social programme for families of children with CF. We had a long session with Alexandre Zashkov, chairman of the parents' charity, Father Stefano Caprio of the Catholic Apostolic Office in Moscow, and his staff of two doctors in which I explained the LIEN Programme in some detail. The Catholics fully understood the implications of the programme and I find them very reasonable, intelligent and co-operative.

I explained that the applicant must be a registered non-profit-making NGO based in a member state of the EU and the partner or partners must be in a country covered

by the LIEN PHARE and TACIS Programmes (e.g. Russia). The applicant must also have a proven record of activity, as we have, in the areas targeted by the programme. Projects ideally biased or partisan in nature (including projects with a religious bias) would not be considered. The Catholics will provide co-funding and will open the centre to doctors and patients of all religious denominations. They talk of the Centre as an ecumenical enterprise.



We have heard that the pharmaceutical company Solvay/Duphar are planning to finance visits by Moscow doctors to train doctors in provincial centres in the latest treatments for CF. This is fine, but we have suggested that it would be more helpful if the visits coincided with some training in the development and management of family support services.

It seems probable that there will be many changes in the coming year which could be negotiated in a sensible, practical way with all groups willing to compromise if necessary to reach their common goals. As I see it, IIHA's role will be:

1. to offer practical help in setting up family and adult support services;
2. to help to improve CF awareness in communities - eg schools, local government - as well as the medical profession in Russia and other CIS republics.;
3. to encourage better communication and understanding between families with children suffering from CF and doctors.;
4. to try to help with public relations, funding and the emotional and economic problems of families.;
5. to try as much as possible to bring divergent groups together in activities that will help to give people involved in our programmes a sense of purpose. The European Commission LIEN Programme, including the IIHA project, *Care of Children with Chronic illnesses and their Families*, is designed to help vulnerable groups in practical ways that go beyond politics.

Peter Kent describes IIHA's role as that of honest broker. He recommends the establishment of a committee involving the Parents Association, the Catholic Church, the CF Department of the Republican Children's Hospital and Quaker Peace and Service. The first step will be to appoint two development workers to initiate the support service.

Life in the Fast Lane

Isabella says that she is a busy person, but when a Russian family of four turned up in Winchester she hesitated for a moment, then absorbed them into her household and was glad of the experience.

The last I heard of them was a hesitant young voice on the other end of the phone: "Hello ... it's Hermann ... we are going back to Moscow tomorrow ... we wanted to say goodbye - and thank you"

They had departed for London a few days before, my unexpected visitors, having stayed with me for ten days or so. Now there was an empty room, sheets hanging on the line, and a pot of white flowers on the kitchen table. They must have known that I like white flowers best.

'I trusted in God and the English'

When they had first arrived from Moscow, and made for the Quakers' headquarters in London, Farida and her children had no idea where they would stay. "I trusted in God and the English", she said later. She had been determined to bring her young son Vova, recently diagnosed with CF, to see Dr Chris Rolles and his team at Southampton. Not strictly necessary due to the work that IIHA and the Southampton team have done in Moscow, but she wanted to make sure that he was getting the best treatment. Phone calls flew back and forth between the Quakers and IIHA. It was lucky that they knew of us. The family was put on the train for Winchester and met by Roy, who took them to his home and made them an appointment to see Chris the very next day.

But Roy and Dorothea could only put them up temporarily in their small flat.

"I'll find them accommodation tomorrow," I promised, when I brought them back from their initial visit to the paediatric unit. Perhaps I could find them a flat for two or three weeks, or failing that, bed and breakfast somewhere. Overnight though my resolve weakened. It seemed mean not to offer them room myself rather than let them spend a huge amount on lodgings? I had a big house.

The constant stream of visitors, family, boy friends, over the long hot summer would just be extended a little longer. If I had fed six or seven the previous evening, then why not another four - only eleven, I thought, it's not that bad!

And so they were installed, all together in the guest room, Farida and Lida in the double bed, Vova in a single bed and Hermann on a mattress on the floor. Four extra toothbrushes were ranged in a neat row in the bathroom. There was little disruption, and only a few remarks from the family about the difficulty of getting a hot bath!

My head was in a spin

It was an interesting day, an unexpectedly good experience, but my head was in a spin when I reached Winchester. No reply on the phone, so I went home by bus and found Farida preparing a wonderful Russian dish of fish, potatoes, onions, aubergines, and so on, garnished with beetroot and peppers.

"Tired ..." she said, meaning me, "sit down ..."

She had little English, but I understood her and agreed!



Photo: Courtesy Hampshire Chronicle

Isabella in her garden with Vova and Roy Ridgway

After a day I had to go to London to the Know How Fund - SPS conference. It started early so I travelled up the night before to stay with a friend. I collapsed on her sofa with a headache. I had to get through the next day then go back to cope with a houseful of - how many? - ten? - I couldn't remember. I achieved two hours sleep that night for my friend had developed a streaming, sneezy cold and in her tiny flat I couldn't escape from the constant coughs and nose-blowing. Thank goodness my immune system is second to none, but the next day my head was even worse (yes - really!) and I realised that I had left my umbrella at the station. However, after half an hour's walk and a quick visit to the Quakers in Euston I took a deep breath and turned up at the conference.

So how did the time pass? Well, five visits in all to Southampton General Hospital, three press interviews, one TV interview, and meanwhile shopping, cooking, and trying to get into the office now and then. Farida loved the shops and went by bus to Southampton about five times, and Winchester too. The children played in the garden, watched films, found a big box of Lego and some jig-saw puzzles, and in the evening did their homework - English, Geometry and Algebra - and Vova read aloud to me in Russian.

Packets of biscuits vanished rapidly

Farida was very keen on healthy eating, and prepared a mixture of grated carrots, sultanas, sunflower seeds and yogurt for

Letter from Farida

In May this year my family had had news - our seven-year-old son Vova was diagnosed as having cystic fibrosis, a very serious genetic disease. In Russia children with CF live only until the age of 15 or 16. In England they live much longer and the doctors can do a lot for the children. I had to give up working to look after my son, and my husband earns a salary of only £120 a month. So we can't afford the life-saving drugs and treatment which cost about £360 a month.

I was feeling despondent about this when the Muslim Congress of Russia offered to pay the air tickets for me, Vova and my other two children to go to England and also gave me some pocket money.



Our only hope of getting some treatment in England was through the Charity IHA. The Quakers helped me to get in touch with Roy Ridgway, director of the charity.

I am eternally grateful to him and Isabella Block for accommodating my children and myself in their homes and for taking care of us during our stay and arranging treatment for my son at Southampton General Hospital. Never in my whole life have I met such kind people.

Farida Matveyeva



Outside looking in. Lida, Vova and Hermann outside the window of Roy and Dorothea's Winchester flat

their breakfast, but they also loved breakfast cereals and hot chocolate. The toaster was a source of great pleasure. Packets of biscuits vanished rapidly. I think her strict rules on no sugar had gone out of the window. She told me that she grew fruit and vegetables on an allotment for her family. I found out that it took three hours to travel there on a good day - five otherwise, and that was just one way. I left them in Farnham to get the bus to London for the last few days. Farnham?

Why, because I picked up a box of shoes there which they were able to add to the suitcase full of clothes I had collected from friends.

I kissed them goodbye at the bus stop, and was sad to leave them. They had trusted in God and the English, and I had done my bit, but I thought how brave and adventurous they were. I hope it was a good experience for them too.

Isabella Block

CHRIS AND SANDRA TAKE ENZYMES TO ODESSA

Chris and Sandra Bell, parents of 17-year-old Zoe who has CF, took some pancreatic enzymes for the CF children who attend the CF Clinic in the Odessa University Hospital. This was Chris's first visit to the Ukraine, where his father was born.

Chris described his thrill at visiting the country of his ancestors, particularly as he went there to bring some good cheer to children with CF. In Odessa he was introduced to Anna and her 10-year-old son Vitaly, who suffers from CF. They found that though living thousands of miles apart the children had problems in common. Young Vitaly, for instance, had home tuition because of bullying at school and this had also happened to Zoe.

The Ukraine family were immensely grateful to the Bells for their gift of enzymes as well as antibiotics and vitamins. Chris and Sandra went round the CF ward in the Odessa hospital and talked to some of the parents, reassuring them about the future and telling them about IHA plans.

STRENGTHS AND DRAWBACKS OF THE SOUTHAMPTON-MOSCOW CF LINK.

Points from consultant paediatrician Dr Chris Rolles's paper to the European C F Congress, held in Brussels this year

There are probably between seven and ten thousand cases of CF in Russia, but due to lack of facilities only about a tenth of these have been diagnosed.

About five years ago the first Moscow cystic fibrosis clinic was set up and over the past two years strong links have been established with Southampton.

The strength of the Moscow unit lies partly in its position within the large Republican Children's Hospital, where it has adequate ward space, facilities for parents and office staff and easy access to radiology, microbiology and biochemistry services.

Its other great strength is in its medical personnel who are highly dedicated, well-trained and with a good record of continuity. They are eager to increase contacts with similar organisations in the West and are willing to try out new treatments and methods of management.

Major drawbacks

The major drawbacks in Moscow are inconsistent financial resources and problems in obtaining the necessary drugs, particularly the pancreatic enzymes necessary in the treatment of CF. Also, despite their skill and enthusiasm, the doctors can suffer much frustration from low pay, poor resources, inability to obtain good journals and up-to-date information, and strangling bureaucracy.

On the other hand, advantage could and should be taken of Russia's excellent tradition of epidemiological and genetic research, and also the links with national and international research already available to the Republican Children's Hospital.

A good way of fostering this exchange, and at the same time improving the doctors' morale is the twinning of the two centres. This is proving very successful between the CF services of Moscow and Southampton. The guidelines here are numerous exchanges between staff at all levels, including physiotherapists, dieticians, microbiologists and students plus the channelling of gifts of drugs and equipment into properly monitored clinical trials and research projects.

Established Know How

Established know-how from Southampton has proved invaluable to the Russians. The pharmaceutical company Duphar/Solvay donated enzymes for a year's clinical trials for Muscovite children, who were then compared with the children of the Southampton centre. Results showed marked reduction in discrepancies

between the two by the end of the year. And, most encouragingly, even discounting the gift of the drugs, this dramatic improvement was achieved at a fraction of comparable costs in the West.



"Established know-how from Southampton has proved invaluable to the Russians," says Dr Chris Rolles.

MAMA '86

A twinning programme between the Women's Environmental Network Trust (WEN) and Kiev's MAMA '86, has been funded by the European Commission's LIEN project. Kiev is one of the most polluted cities in Europe. 85 km away from Chernobyl, the city has been exposed to constant low level radiation since the nuclear disaster in 1986. This is compounded by the 42 industrial plants in the city which churn out 300,000 tonnes of toxic wastes into the air, water and soil every year. There are clear indications that radiation, combined with industrial pollution, damage human health in the area, and experts describe the immunity problems common in Kiev children as Chernobyl Aids. Children born between 1985 and 87 are particularly badly hit, and have the highest morbidity rates.

MAMA 86 encourages mothers and children to take an interest in their own health and the health of the planet. It also organises practical help for families monitoring children's health, in their independent laboratory in Kiev. A full-scale two-year twinning project, with the aim of sharing experience and skills, is now under way. There are many similarities between the aims of the WEN-MAMA partnership and IJHA and a meeting has been arranged between the two groups in November when MAMA staff and volunteers visit London in a three week training and skillshare.

IIHA'S OFFICE - A STONE'S THROW FROM WINCHESTER CATHEDRAL



IIHA's office is a stone's throw from Winchester's beautiful 900-year-old cathedral. It is housed in an 18th century red brick building, which John Keats and Jane Austen probably passed many times when they were living in the city.

Looking out of the window on a summer's day you can see groups of young people relaxing under the trees and around several weathered old grave stones, talking, picnicking, playing instruments, enjoying the ambience of a small patch of England's green and pleasant land. If they wore different clothes it could be medieval Winchester!

So it's very pleasant working here and we

owe a debt of gratitude to the Winchester Council for letting us use the office at a nominal rent.

This is the creative centre of our East-West initiatives, where ideas are discussed, appeals made, plans worked out and programmes launched. We are in daily touch with leading healthcare experts in Britain, Russia and the Ukraine.

This is where we burnt the midnight oil some months ago filling in that complicated LIEN questionnaire from Brussels which resulted in aching backs, squinting eyes- but a grant of 150,000 ECUs. So maybe Browning was right: most of our joys are three parts pain!

Dorothea Ridgway

Staff

Permanent members of the staff are:

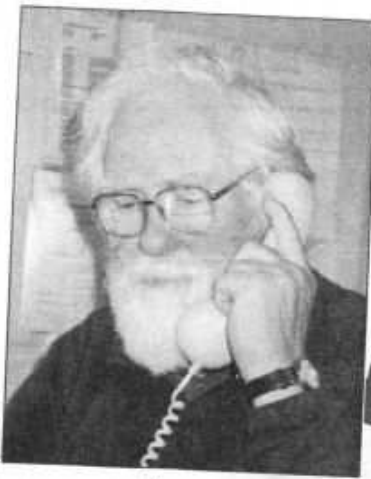
Roy Ridgway: Director. A medical journalist; former Editor of BMA News Review and author of six books, including *The Unborn Child* (Wildwood House, 1985) and *Preparing for Parenthood* (Penguin, 1992). He was European

Public Affairs Director of the International Physicians for the Prevention of Nuclear War, which won the Nobel Peace Prize in 1995. He worked with the UK-USSR Medical Exchange Programme (now HealthProm) before founding IIHA in 1992.





Dorothea



Roy



Isabella



Eve



Anthony



Jenny

Dorothea Ridgway: Has a background in fine art and graphics, and worked in advertising (J. Walter Thompson) and public relations. Trained as a teacher at King Alfred College Winchester and worked for twenty years with children, including disturbed children at the Rosemary Portal School, Winchester. Dorothea is IIHA's CF Project Co-ordinator.

Isabella Block: Treasurer. After graduating in Applied Chemistry at Brunel University she worked with Beecham Research Laboratories as an analytical chemist. She subsequently worked as a computer analyst/programmer at Southampton University library.

Eve Langford: Public affairs executive. She worked for four years in public relations and art marketing at Winchester's Theatre Royal.

Anthony Patterson - Moutray Database work and record keeping. An old Wykhamist, he graduated in economics at Southampton University and later worked with LeHane Consultants where he was the author of a report on the recycling industry in Europe.

Jenny Stables. Heads IIHA's team of interpreters and translators. She is interested in maternity and child healthcare and is the author of *A Mother's Guide to Breast feeding*. (W H Allen 1981)

Among our Russian translators and advisers on Russian culture and politics are: Svetlana Wainwright (wife of IIHA's Secretary Brian Wainwright) and Brian Standfield, who for many years was a translator with WHO.

Consultants

Among the consultants who work on IIHA's health care projects are:

Rev Simon House: IIHA's most active trustee, who is working with Professor Michael Crawford, director of the British Institute of Brain Chemistry and Human Nutrition, on our Health of Future Generations Project

Michael Dibdin: Chairman of the Doctor-Healer Network and member of the Islington Stress Management Committee, he is mainly responsible for co-ordinating IIHA's work with Moscow's First Medical Academy.

Howard Kent: Director of the Yoga for Health Foundation (Ickwell Bury, Bedfordshire), he works closely with Michael Dibdin in developing IIHA's Holistic Health programme.

Peter Kent: Director of Family and Adult Support Services, Cystic Fibrosis Trust, he works closely with IIHA on the development of family support services in Russia and the Ukraine.

Susan Van Dias: psychotherapist trained under Anna Freud, she has worked with children and families at the Tushinskaya Children's Hospital Moscow. She has joined IIHA's team working with the Care of Children with Chronic Illnesses and their Families, which is part of the European Commission's LIEN/Tacis programme.

Dr Chris Rolles: Consultant paediatrician at Southampton General Hospital, director of IIHA's Moscow-Southampton CF Project. His counterpart in Moscow is Professor Nikolai Kapranov, head of the CF Department, the Republican Children's Hospital.



Olga Gorodinskaya, the 12-year old sister of Odessa business woman Oksana. She has cystic fibrosis and comes to the Royal Brompton Hospital in London for regular treatment. A letter from Oksana to the British Department of Health led to the IIHA project, the Care of Children with Chronic Illnesses and their Families in the Ukraine. So in future Olga will be getting her treatment in Odessa.

Dr Mark Rosenthal: Consultant respiratory paediatrician at the Royal Brompton Hospital, he heads the British medical team working with IIHAs Care of Children with Chronic Illnesses in the Ukraine.

Dr John Stephen: retired GP who is an expert on Primary Health Care in Eastern Europe and the CIS. He is working with IIHA and the Royal College of General Practitioners on IIHA's Primary Health Care Project in Odessa.

International Integrated Health Association
Registered office: 3 The Square, Winchester SO23 9ES
Tel/Fax 01962 865 858

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NEW TRADING COMPANY WILL DONATE PROFITS TO CF CHARITIES

A new trading company to sell household goods, glassware, porcelain, leather, toys, giftware, pottery and possibly wine produced in the republics of the former Soviet Union will donate its profits to IIHA and the Odessa CF Trust. A study is to be carried out on the viability of such a company and approaches will be made to potential buyers. The company will operate separately from IIHA and no funds donated to IIHA will be used to finance or promote the company. This is an initiative of Oksana Gorodinskaya, an Odessa business woman, whose sister Olga has cystic fibrosis. Oksana wrote to the British Department of Health in 1994 appealing for help for her sister. The Department asked IIHA if we could help. When we said yes they financed a feasibility study in Odessa, carried out by IIHA and the Royal Brompton Hospital. The result was our project the Care of Children with Chronic Illnesses and their Families in the Ukraine.

SEARCH FOR A CF CURE

Britain's Cystic Fibrosis Trust was founded in 1964 for the purpose of raising funds to finance research to find a cure for cystic fibrosis and to improve the care and treatment of people with CF. Then about five years ago it widened its aims to include the establishment of family and adult support services with branches and groups throughout the U.K.

These aims are, of course, complementary, but in some other countries they are regarded as separate issues. And this is true in France, where one charity raises funds for research while the other concentrates on the social and psychological needs of families.

In Russia members of the parents' committee also treat the two operations as separate and even question the value of research, believing, rightly or wrongly, that much of the research that is going on in Moscow is of no immediate benefit to patients. At the same time, it is difficult to find funding for research from the charities who support IJHA, but medical exchanges which they do finance and provide intensive training for Russian doctors in the treatment of CF, also provide opportunities for valuable research which has as a matter of fact formed the basis of papers presented at international conferences in Brussels, London and Dallas. Both the Moscow Republican Children's Hospital and the Southampton General Hospital are rightly proud of this collaborative research which has attracted world-wide attention.

However, the really important research, which may come up with a cure for CF, is being carried out only in the West. In the U.K. large sums are being donated by the CF Trust to doctors engaged in research to find if a cure is possible through gene or drug therapies.

Gene Therapy

The CF Trust Annual Review (published in October) describes the nature of this research. The faulty gene in CF contains chemical instructions for making a 'pump' in the membranes of certain cells. Because the gene is faulty the instructions are incorrect and the pump doesn't work properly. Obviously if this faulty pump activity can be corrected the problem will be solved. One approach is gene therapy which hopes to be able to replace the faulty gene with a normal copy. But this is an enormous challenge and although the work so far has been encouraging no-one is certain that this kind of therapy can be developed so that it is clinically safe and effective.

Research to establish a safe method of gene therapy is now being carried out at the Royal Brompton Hospital and St Mary's Medical School, London, but there is still a long way to go before doctors will know the answer to this problem.

Drug Therapy

Another approach is through using drugs to repair the faulty pump or bypass it altogether. But at present no-one has a thorough understanding of the structure of the pump and how it works. So the research going on now is of an exploratory nature. It is known that the pump is like a tube passing through the cell membrane with a series of on/off switches controlling the flow of salts and water in and out of cells. Researchers in the Molecular Medicine Centre in Edinburgh hope their present research will lead to an accurate description of the faults in the tube and an indication of how they can be corrected.

1995 NOBEL PEACE PRIZE WINNER

Congratulations to Professor Joseph Rotblat, the British anti-nuclear weapons campaigner, who has been awarded this year's \$1 million (£635,000) Nobel Peace Prize. Professor Rotblat was an active supporter of the International Physicians for the Prevention of Nuclear War (IPPNW), which was awarded the Nobel Peace Prize ten years ago.

"I first met Professor Rotblat in his Bloomsbury office when I was editor of BMA News Review," says Roy Ridgway, formerly European press officer of IPPNW. "I was gathering information for a feature article about the meeting of Russian and American doctors who had met in Geneva and had issued a joint statement condemning the stock piling of nuclear weapons. My article, called 'Four Minutes to Midnight', led the BMA to set up a working party to study the medical effects of nuclear war.

"I remember how quietly confident Professor Rotblat was. I came away with the feeling that I'd met a scientist who knew what he was talking about. There was no emotional bluster about his opposition to nuclear weapons. He let the facts speak for themselves. The article I wrote went round the world and, because it was endorsed by the BMA, succeeded in persuading many doctors to join the anti-nuclear campaign."

Professor Rotblat was a speaker at many of our meetings and was present at the House of Lords meeting of the Renaissance Group when our President, the Australian nuclear physicist Sir Mark Oliphant, spoke.

Mark Oliphant and Professor Rotblat both worked on the Manhattan Project, which developed the first nuclear weapon in Los Alamos, New Mexico. Now aged 86, Professor Rotblat is the only survivor of a group of 11 scientists, including Bertrand Russell and Albert Einstein, who came together 40 years ago and issued a protest against the new weapons of mass destruction.

HEART APPEAL

Each year 20-30,000 children in Russia suffer from various heart disorders. More than 13,000 of them require surgery, but only about 4,000 of these can be operated on in Moscow. The others face a grim and hopeless future unless they can get help from abroad.

Vera Basis was fortunate enough to be able to raise funds to send her own daughter, who had a heart problem, to the USA for an operation which saved her life.

Vera then decided she must try to help other children who, like her daughter, were in need of surgery or treatment, which they couldn't afford, and in 1992 she founded the Society for Children with Cardio-vascular Diseases. Its chairman is Professor Vladimir P Podzolkov, the distinguished heart surgeon at Moscow's Bakulev Institute for Cardio-vascular Surgery'

The aims of the Society are:

1. To identify children with heart disorders who are in need of urgent assistance
2. To define the kind of assistance needed - whether humanitarian, social or medical.
- 3 To seek help by appealing for donations from charities and sponsors

The society has been able to obtain the support of a number of sponsors including the Red Cross and Salvation Army and has been promised

some help from the Russian Ministry of Health.

Achievements

Its achievements include raising funds to send children abroad for heart operations, purchasing special equipment and drugs for the Bakulev Institute and for the Centre for Rehabilitation of Young Heart Patients.

The Society also does its best to help families of children with heart disorders.



The Society is unable to meet all the demands made on it to help in obtaining medical supplies and they are painfully aware that time is one thing the young heart patients do not have at their disposal.

Sometimes they die through lack of essential drugs that are too expensive or cannot be obtained in Russia. They also suffer through the absence of simple things like gauze and bandages.

The Society is being helped by students at Moscow's University for Economics and Business Management.

One of these students is Vera's daughter Leda and another is

Andre Nesterenko, who is the son of a diplomat at the Russian Embassy in London. His father recommended him to get in touch with IIHA and as a result of this Roy Ridgway met him and Vera Basis and two students at the Canadian Club in Moscow in October.

Partnership

The Society has similar aims to IIHA and was founded in the same year - 1992 - so we decided to form a partnership for the purpose of raising funds for drugs, for training doctors at Bakulev Institute in cardiological surgery techniques, and for help with the social and psychological needs of families.

We intend to apply for assistance for funds from the European Phare/Tacis LIEN programme and are working on proposals for the second round of applications in April. But in the meantime there are many children urgently in need of help, so if you would like to contribute please write to: IIHA, 3 The Square, Winchester SO23 9ES, marking your envelope HEART APPEAL.

In every child who is born, under no matter what circumstances, and of no matter what parents, the potentiality of the human race is born again. And for all of us every child is a reminder of our terrific responsibility towards human life.

James Agate

Mankind owes to the child the best it has to give.

U.N. Declaration

Planning for healthy babies in the CIS

The republics of the CIS are far behind the West in most aspects of health care provision. This is variously a product of shortage of funds, a creaking health infrastructure and lack of education about health amongst the population at large. These problems are especially applicable in the case of eating habits and nutritional standards and probably nowhere more so than in the area of nutrition for reproductive health. For example, Russian studies show that the plasma level of Vitamin C in many mothers is often far lower than recommended and poor nutrition is probably the major factor in the high incidence of pathological conditions seen in the newborn in Moscow.

Decline in public health This is part of a serious decline in public health which is happening against a background of financial instability, deterioration in the standard of living, political disintegration and complete lack of faith of most Russian people in their rulers combined with fears about a future collapse of the government and the return of a dictatorship.

To help remedy this state of affairs, a number of voluntary organisations in the West have set up health partnership schemes with Russian and Ukrainian medical institutes and NGOs. They are working together to try to stem the decline in health standards by helping in the reform of the healthcare system and by providing humanitarian aid for disadvantaged groups.

IIHA in Odessa

IIHA is involved in helping disadvantaged groups in Russia and the Ukraine. In the Ukraine we are working in partnership with the Cystic Fibrosis (CF) Trust of Odessa and the Odessa University Hospital. But apart from CF we are turning our attention to a programme to combat the ill-

health of many women in the region, who suffer from the effects of environmental pollution and poor nutrition.

Decaying industrial base

The deprivation in the port of Odessa, where we are working, is associated with a decaying industrial base, which because of its strategic location on the Black Sea was once the Soviet Union's greatest naval centre. Odessa is twinned with Liverpool, and shares similar problems stemming at root from the long-term decline of its ship-building industry and freightage business. As in other parts of the former Soviet Union insufficient consumption of fresh foods is widespread and results from problems of availability, cost and food knowledge. The results of this problem are nowhere greater than amongst women of child-bearing age. For this reason IIHA is planning a programme, called Health of Future Generations which puts special emphasis on the nutritional status of men and women of reproductive age.

Training specialists

We are planning to introduce such a programme in Odessa, Moscow and Kiev. It will begin with the training of specialists in maternity and child healthcare at the Institute of Brain Chemistry and Human Nutrition and at Dr Wendy Doyle's Mother and Baby Clinic at Homerton Hospital, London.



The course will be organised by the distinguished biochemist and nutritionist Professor Michael Crawford, who recently won the coveted International Award for Modern Nutrition, and is the author of *Nutrition and Evolution*, which has just been published in the U.S.A.

The early stage of life, when dividing cells are laying the foundation of the nervous system,

are the most vital time for building good health for lasting effect. This is the aim of our reproductive health programme. And we plan to combine this with a psychosocial approach, to minimise threats to the child's mental and emotional stability because of maternal anxiety before the child is born.

A partnership with the Odessa University Hospital (the Pirogov Medical Institute), has been established to implement our plans. This will be under the direction of Professor Boris Reznik in Odessa. At the same time, we plan to carry out a research programme large enough to give statistically significant results on infant disorders.

In Moscow the scheme has been welcomed by Professor Alexander Baranov, Chair of the International Fund for Maternal and Child Health Care, and by Russia's top nutritionists; and in Kiev by heads of Family Planning and of Paediatrics, Obstetrics and Gynaecology, and a specialist in the Ministry of Health. **Simon House**

RUSSIAN DOCTORS' SALARIES BELOW THE POVERTY LEVEL

Dr Vyacheslav Alexeyev writes (BMJ, 7 Oct, 1995): In Soviet times lack of funding of the health service was partially compensated by the medical community's high ethical standards and professionalism. In a society where almost everyone earned more or less the same amount, professionalism was one of the few ways of gaining social recognition.

Today the average salary of a surgeon is £45 a month, and according to the trade union of medical workers, over 70% of Russia's health care professionals now receive salaries below the official poverty level of 321,000 roubles (about £53). A third of Russians earn less than the recommended monthly wage, including a disproportionate number of doctors.



Wills

Jane Freeman explains why you need one



The sorry fact is that the vast majority of people who are asked the question "Do you think you should have a legally valid will?" answer, "Yes - I must get around to it!" However seven out of ten people die intestate (without a legally valid will) often leaving their loved ones a legacy of unnecessary problems at what is already a very distressing time for them.

The testator of a legally valid will may direct exactly who is to receive his/her property on death and on what terms taken, and more importantly, avoid the consequences of the laws of Intestacy. These laws are often assumed to be fairer than they really are. The fact is they often lead to property passing to relations you would not wish to benefit, while leaving loved ones suffering unnecessarily.

If you are married with no children and you die without making a will your spouse will get the first £200,000 and personal chattels plus half the balance of the estate. The remainder will pass to your parents. If they have both died, it will pass to any brothers and sisters you may have. Whilst they may be honourable and gift it back to your spouse or children, this could in itself create a tax liability. All this uncertainty, and costly- and time- consuming business, can be avoided and your wishes respected if you write a legally valid will.

If you are married with children and die without making a Will then your spouse will get the first £125,000 plus the personal chattels but only the interest only from the remaining estate. The other half will go to children immediately or will be held in trust for them to have when they become of age. This again can create difficulties with a family unit, possibly the family home will have to be sold to pay off the beneficiaries.

The Herald of Free Enterprise capsizing is a tragedy that we all recall. This disaster brought much misery not only through the sad loss of family members and friends but also in the aftermath to many ordinary people who suffered the consequences of The Laws of Intestacy. We all have a duty to protect our families from such financial suffering.

If you are legally separated from your spouse or are unmarried and co-habiting, expressing your wishes in a legally valid Will takes on a special significance. Your spouse/partner will

not automatically inherit your goods and property under the Laws of Intestacy.

Making a will gives the testator control. A gift may be made conditional, say, on the beneficiary reaching the age of 21 or 25 if the Testator considers 18 too young for the beneficiary to inherit. Property may be disposed of "absolutely" or alternatively through a trust created in the Will. You can thank a friend who has shown you support by a legacy to charity favoured by them.

Making a will also enables the testator to exercise his/her own choice in the appointment of Executors to administer the estate. This ensures that somebody the Testator trusts can be appointed and that heavy professional fees can be avoided in many cases.

Making a will provides an opportunity to consider the statutory powers of the executors and trustees and extend them where appropriate, in order to make their work easier and less costly.

Making a will provides opportunity for choosing and appointing guardians for your children under the age of 18 to ensure the safety and well-being of your children if the unthinkable should happen.

Making a will as part of a properly planned estate provides an opportunity for the Testator to avoid unnecessary Inheritance Tax which could otherwise result in hard earned money being given to the state, property may even have to be sold to pay of this Tax liability.

Making a will gives the Testator the chance to express a preference as to the burial and disposal of their body.

Making a will ensures that your dependants obtain the benefit you wish from your business or partnership.

Making a will through a practice specialising in Estate Planning can avoid much unnecessary unhappiness to those you leave behind. Preparing and making a legally valid Will could be the most important step in your life - if not to you then certainly to those you leave behind.

Your Last Will and Testament are not only an indication of responsible action but also a sign that you really care about your family and loved ones. We never know what is around the corner and only one thing is inevitable for every individual. Even if we do not talk or think about it, it will not go away. "Too busy", "too young", "too poor", are rarely valid excuses, if you do not have a Will, for your families sake do not put off this most responsible act any longer. If you have already made a Will please check the details regularly to ensure that it still reflects your circumstances and your wishes.

If you wish to write or rewrite your Last Will and Testament and perhaps leave a legacy to your chosen Charity call Jane Freeman on

01705 465328 (Ref:

IIHA)

Phone and Fax

The Will Writing Bureau

Regulated by The Society of Will Writers

Freeman and Framp Legal Services

Estate Planning Consultants

**Fieldside House St. Peters Road
Hayling Island, Hants. PO11 0RT**

**WHERE
THERE'S A
WILL
THERE'S A
WAY
AHEAD**

IIHA is always in need of funds to help extend its work and assure its future. As part of our forward thinking, we now have an arrangement with Freeman and Framp Legal Services to help you write your will as part of a properly planned estate. This is a free service and includes advice on leaving a legacy to a chosen charity. Services include:

- Last Will and Testaments
- Codicils
- Executorship
- Guardianship Protection Plans
- Golden Charter Pre-Paid
- Funeral Plans
- Financial Planning
- Inheritance Tax Planning

N.B. On the completion of any transaction the cost of any phone calls or postage will be refunded either by a credit directly to the individual concerned or it can be credited to the IIHA administration budget.

Jane Freeman, who is a member of the Society of Will Writers, can advise on the laws of succession and intestacy, the appointment of executors and trustees, both professional and private. She will advise on legacies to family, friends and/or your chosen charity.

Using any of the services of Freeman & Framp will help IIHA who will receive an introduction fee on completion of a transaction on any service. Jane will look after and advise both IIHA members, their families and friends and also colleagues on a personal basis.

She will be writing on each of the services offered in IIHA News from time to time and we hope this proves interesting and informative reading to our members. Her first topic Wills is published in this issue which we hope you will find interesting. If any of you have a related question of general interest, please write or fax Jane who will reply to you directly and publish the question and reply in IIHA News. (privacy will be respected.)

Complementary Therapies in Moscow

Professor Vadim Zilov, IIHA's Moscow director, who is head of the department of Complementary Medicine and Clinical Physiology at the First Medical Academy (I M Sechenov), and Dr L Kudaeva, deputy director of the department, visited the UK from 26 August and 17 September.

As on the previous visit in July, 1994, this was financed by The Know How Health Care Small Partnership Scheme. It was the fourth visit by a delegation from the First Medical Academy since IIHA started a co-operative working arrangement with them in 1991 to look at the practical application of complementary therapies in a conventional medical environment.

This time our colleagues came to gather information in the following areas:

- Research into complementary therapies
- Stress management
- Child health care
- Training of nurses in general and in complementary medicine in particular.
- General practitioners in the UK and their participation in complementary medicine.

It is estimated that 70% of the Russian population is currently suffering from stress and its related ailments, so the Russians found a visit to the pioneering Islington Stress Project particularly fruitful and interesting. It tied in well with their participation in a WHO-supported conference on stress in Moscow earlier in the year and a visit to Leeds to meet David Bray of the International Stress Management Association.

The sharp decline in the Russian pharmacological industry resulting in an acute shortage and spiralling costs of reliable drugs, combined with concern about their side effects, has triggered an interest in complementary therapies. Interest in folk medicine survived the Communist years when it was not encouraged, though practised widely in rural areas, and there is now a much respected Institute of Folk Medicine in Moscow. Russian hospitals today use electro-magnetic and other medical equipment that in the West might be regarded by many doctors as hocus pocus. Distinguished scientists in the academic town of Troisk are investigating "subtle energies", including dowsing. Russian doctors are on the whole less sceptical about alternative medicine than their counterparts in the West. Now the Russian Ministry of Health has officially given its

blessing to the use of homeopathic remedies in hospitals and clinics within their state health service.

That is why our colleagues were keen to meet homeopathic physicians, in the UK.

They had meetings with Dr Peter Fisher, director of clinical research at the Royal London Homeopathic Hospital, and Dr Peter Chappell, a director of overseas training in the London College of Classical Homeopathy. There were discussions about the possibility of inviting Dr Chappell to Moscow to run an introductory course on homeopathy.

Non-conventional therapies have been accepted in many areas of conventional medicine in the U.K. and this was highlighted by discussions our colleagues had with Professor Alexander Russell, Council member of IIHA, who is a prominent paediatrician and advocate of the controversial Hungarian Peto method of treatment for cerebral palsy. Professor Russell is keen to open a Moscow centre for disabled children and their families and this seems a distinct possibility.

The visit was rounded off with a meeting with Dr Philip Evans, Secretary of the International Committee of the Royal College of General Practitioners, to carry forward the discussions on primary health care in Russia and the need to introduce a system of primary care more like our own in the UK. A presentation on general practice to the family medicine department of the First Medical Academy is being planned by IIHA and this will probably take place early in the New Year.

GUARDING AGAINST STRESS

A Russian company Health Guard Ltd has developed a number of early-warning devices designed to prevent disorders of vital physiological functions. They include a portable instrument (SOS) which gives a warning signal in the case of heart dysfunction, arrhythmia and ischaemia.

Another called Baby records irregularities of the fetal heart from the 20th week of pregnancy. A third, which can be worn like a wrist watch, registers pulse rate and warns of any rise in blood pressure. There are devices for guarding against stress and one remarkable device, a physiological clock, which switches on at night before waking and ensures that a person wakes up feeling relaxed.

Health Guard is a member of Russia's Regional International Stress Management Center which is a department of the Russian Academy of Medical Sciences' P.K. Anokhin Institute of Normal Physiology.

HELPING FRANCESCA'S DREAM COME TRUE

Lena Hyltoft, who worked for a year as an English teacher at Moscow's Children's Home No 12, describes how Francesca, once an inmate of the orphanage but now living in America, dreams of the day when her little Moscow friends will have a playground of their own like the one she now has at her school in Massachusetts. IIHA hopes to make her dream come true.



Francesca in Moscow's children's home in 1993

It is now two years since I spent a year in Moscow, where I had a chance to work at Moscow Children's Home No. 12 (an orphanage caring for children with special needs from the age of 0-5) teaching English to a group of 3-5 year old children, who were awaiting adoption by American families.

During the winter months of 1992-93 I taught my little pupils indoors; as soon as spring arrived we took our picture books, guitar and songs out into the derelict and uncared for grounds attached to the home. When summer approached the nannies would take all the children out here to sit in the sun. But there was something missing! There was nothing for the children to do here... there were no play structures except for a rusty old fence with a circle, and a couple of shelters which had been vandalised to the extent that they would not even suffice as cover in the event of rain. The staff at the home lamented the lack of recreational facilities and recognised that this also severely limited the children's outside activities.

In the summer of 1993 Judy Melillo arrived at Children's Home No. 12 to adopt 5 year old Francesca. Judy had to spend some time in Moscow with Francesca before taking her back to America, and she often took her for walks in the dilapidated garden. When Judy saw these bleak surroundings her immediate thought was very similar to mine...there is something missing...these kids have no playground structures! Now Francesca Melillo is 7 years old she loves going to school and spending time in the playground. Her life in America has opened up a new world of play, fun and activities with other children, provided within the space of a children's playground. Francesca is happy now, but she has one concern...she wishes that her little friends that she left behind at Children's Home No. 12 could play and have fun like she does now.

When Roy and Ben visited Children's Home No. 12 in autumn 1994, they were told that the number of children at the home had increased. At IIHA we would like to help realise a playground facility, which would give the children who spend their young lives there in the future a possibility to play and interact as other children would do at a kindergarten, or in a public playground.

"Francesca's playground" will be one of our projects at IIHA for Children's Home No. 12. I told Francesca that we would try to help her wish to come true and she said:

*"I am so happy
if a playground
can be built
for my friends
at the home.
I wish for my
friends to have
a playground so
that they will smile
and know how to
do things like play
on the swings."*



Francesca in America this year

DIARY

Roy Ridgway

Have decided to start each day with a writing meditation. The first hour of the morning is important in putting you in the mood for what the Buddhist describes as "right action."

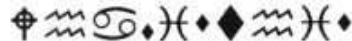
Memories come flooding back. Remember my Thought for the Day which ended my report every morning after a night working on the porters' lodge in Gloucester General Hospital - a dreary, miserable job - during the war.

The thought last night just before going to bed was a quotation from Thomas Hood:

Heaven gives our years of fading strength
indemnifying fleetness
While those of youth a seeming length
proportioned to their sweetness.

Was it this quotation that made me think this morning that I must not waste the precious little time I've got left? But must not panic. Am always rushing to get things done. It's OK to work fast - not because one mustn't waste time, which is the work ethic - but because being and doing are in harmony. The sensitive, attentive mind is quick to see things and quick to act. Out of non-action comes action. Out of pre-planned action comes repetition.

After my morning meditation went into the sitting room and tripped over a rolled-up carpet.



"Hell!" I screamed. I could have fallen and broken my leg. That's the way I think at my age. The meditation hadn't helped much. But felt better when on the way to the office I passed a bank of snowdrops in the church garden as the clocks in the city were striking ten, and was delighted to see almond and cherry trees in blossom. Spring has come early this year because of the mild winter.

There were two letters for me in the office, both from FAU friends - one from the artist Paul Mount containing £10, and the other, also containing £10, from Keith Thompson. Keith says he parts with the money reluctantly because Russia has spent money on armaments and on the Chechnya war instead of on children and says his family suffered - he doesn't say how - because of the Russo-German pact during the war. "Old wounds still hurt," he says. He also has an incurable cancer. No wonder he sounds angry.

Transforming misery

Had a restless night. My nose was blocked and had difficulty breathing. Got up once or twice with an upset stomach, the result of a large supper last night cooked mainly for friends. Felt like a piece of chewed string this morning and wondered how I could do my writing meditation. Here am I starting on a negative note. But one can turn every experience into something interesting and creative.

Night is a period of creation when problems are solved by the unconscious. But sometimes I remain awake to wrestle with demons that hover above me, their green eyes staring down. But in the morning all is well - a battle has been fought and won.

Dorothea's friend L is a tormented soul and now has a heart condition, but she writes beautifully about her troubles. The other day she wrote to Dorothea about February "It is the subtlest, most atmospheric month, everything in nature is there in essence waiting to happen, and giving off little inklings of the Spring. Out in the Fens where there's an infinite expanse of sky, vanishing perspectives and incredible plasticity of form, the best days are at this time of year."

L says she has a manic, do-or-die way of working. "The question is," she writes, "are we in these various states of decay because of having fulfilled our destinies and achieved what we were meant to achieve? Or is it because we have abused ourselves and done things the wrong way? How long or short my life is isn't all that relevant: what's important is doing something really useful in it. Is that vanity? Each day I feel I'm on the threshold of fulfilling a great purpose: then it just turns into another round of breakfast, lunch, tea, shopping, mucking out, mother, housework and bed." And so she goes on. In between visiting doctors she staggers about in frozen dykes to rescue swans from rat-infested rivers at dead of night. Night again, the terrors of night. Everything seems worse at night if you're doing an unpleasant job. L drives round in a car full of guano, clutching her mobile phone in case she gets "a funny turn." Could she write so well if she wasn't tormented and neurotic? I think not.

Swan
Upping in
a frozen
dyke



Cardinal Newman described writing at its best as "the poetry of the soul." It could also be the poetry of hell. In fact for most of us expressions of hell are more interesting and more true to life than the sweetest, most heavenly songs poets ever wrote. Bosnia, Chechnya, Ruanda and so on - the wounds of today which will go on hurting for many years to come. The most compelling stories by journalists and the most moving photos come out of these tragedies.

A problem of style

I very often write without feeling, because it's my job as a medical journalist to report what I hear and in this sort of reporting my own views are not wanted. My writing is tight and factual; I'm not in touch with my feelings. So the first person perspective is missing and I miss the meaning. I was trained to write in an unfeeling way about medicine because modern medicine has turned us all into objects to be studied, analysed, taken apart; and what's happened is a fear of saying anything that is tainted with emotion.

I look at a blank piece of paper, or more likely these days a blank computer screen, and at first I'm not sure what I'm feeling. Decide to be more attentive. As I'm writing this, for instance, there's a woman's soprano voice coming from a radio in the sitting room, a welcome distraction. Don't have to look inwards. My head is full of music. I hit the various letters of the keyboard with one finger. Don't know where my words are coming from but suddenly they're there on the screen making patterns out of what is happening.

Someone once wrote as he struggled with a poem about dying: "Death is a smell no longer. It's a problem of style." It's what we make of what happens that matters. The universe is sublimely indifferent to anything we feel unless it's translated into action!

A new country

I reject Shakespeare's image of an old man as a "slipped pantaloons." I don't feel as useless as that though society treats me as if I should put my feet up and stay at home watching television or go out to the village hall to play Bingo. That's not me!

The secret of growing old is living and being in the present - with full attention and a full heart. Not singing and dancing and pretending things are not what they are - but paying attention to whatever is going on, being interested, living and understanding whatever is happening. The present is the only reality we have, that can be seen and felt and grasped, whether we're young or old. In this one respect we're no different from one another. It's time, or the way we perceive it, that separates us. Time, of course, brings its problems. We get weaker as we grow older, but besides our aches and pains it's our failure to live in the present, our pining for the past and our fear of the future that makes us feel really old. It's our approach to age that is what matters most. And personally I have found a "just

being" philosophy is what helps me more than anything else.

In old age short-term memory is not so good and skills are lost of course. When the famous American baseball pitcher Lefty Gomez was warned that he was not throwing so hard as he did once, he replied, "I'm throwing twice as hard, but the trouble is, the ball isn't going so fast." But if skills are lost so is the desire to be a winner all the time. Winning is no longer so important. You don't need to work so hard because you are not trying to prove anything. You aren't going anywhere. You've arrived.

There are lots of good things about growing old. For one thing it's a new country, a new place to explore. So it's like being young again, wondering what's coming next and being thrilled with everything along the way. You are free to be what you want to be; many of your inhibitions go, sex doesn't bother you so much, although contrary to what people say of old age, interest doesn't wane. The world is an even more wonderful place, and in the end you can step out of the comedy/tragedy without fuss or bother. Slip away if the doctors will allow you. Dying is not so awful as it seems in youth. It's sometimes welcome.

A year or so ago a friend, who had been back-packing in Nepal, returned from his holiday to find he had cancer of the liver. He didn't live long after that. My wife Dorothea and I were with him in the Royal Free Hospital in Hampstead a few days before he died. It seemed ridiculous to see him lying there looking sunburnt, the picture of health. His hand grip was as firm as ever as he greeted us. He asked us to draw the curtains so that he could see the sky. And his last words to us were: "This is going to be an interesting experience." Memorable words, like those of the American writer O'Henry who, as he was dying, said: "Don't turn out the light. I don't want to go home in the dark."

Replaying the DNA code

I think of dreams as replaying the DNA code, reviewing what is going on and informing me just where I'm going wrong.

I remember bits of dreams I had last night. I was in a country house with my brother Alfred and other members of my family who are dead. They were leaving me there and I felt lonely and confused. Then I was in a room with some suitcases which I was packing. There was too much to put in them. I couldn't find some books I had. I concluded that my son Tony, who died eleven years ago, had taken them. Then I was on a bus with someone, an authoritarian figure, who told me he was staying behind, but I didn't know where I was going.

Dreams hold you in their grip, but they are often baffling, saying things your conscious mind doesn't understand. I woke up with the confused feelings of my dreams. I am alone - is this the lonely child seeing things, describing his feelings? Many of the people I

have loved are dead and the house is empty. I cannot reach them. The lonely child in me is calling out to them. but they are not there. They are not responding. I feel something of that emptiness I felt as a child, although I don't feel unloved today: In a sense, my life today is too full. I have too much to do, too many friends. I don't know where I am going. I am leaving authority behind. I don't need rules where I am going. I haven't the knowledge of my young son Tony, who suffered from cystic fibrosis and lived with death all his short life. Death is not part of my luggage. as I'm sure it should be.

Grief observed

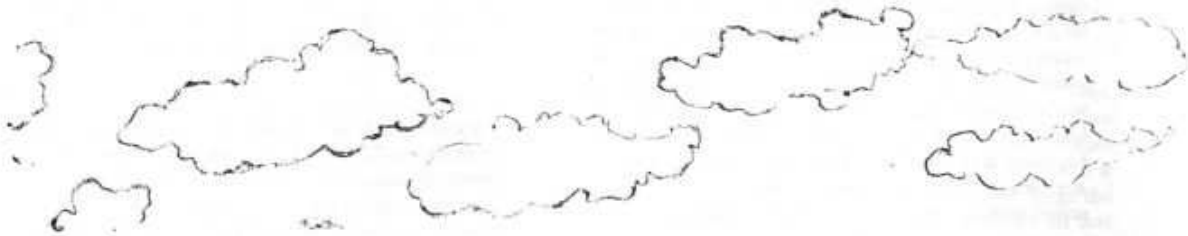
Pleased to receive copy of *Self and Society* containing my article called *Articulating Grief* which is about Tony's death and about charting patterns of grief as C.S. Lewis did so movingly in *A Grief Observed*. When I showed Dorothea the article she said she didn't want to read it because it brought back too many painful memories but in the end she succumbed. "It's good," she said, "but I don't want to talk about it." For me

writing about painful feelings is more than cathartic - it is completely transforming. Something new and even beautiful is created out of the misery. I explained to Dorothea that I wrote the article because death had a way of belittling you, and writing restored your faith in yourself. "Painting does too," said Dorothea.

Meeting in Paradise - or the other place!

Rex Raab, an old friend of FAU days, now in his eighties, wrote in response to a letter I wrote about a cancelled meeting ten years ago: "Even if we didn't succeed in seeing each other then, perhaps we will be visiting each other more frequently in ten or twenty years' time!"

He writes about the "uphill work" of IHA and goes on: "Is there any worthwhile work these days that is not uphill? There are downward pulling forces at work all the time, but we suffer especially through not facing up to them.... At least it is a challenge for some people and the rest lean heavily on them."



Jim Grant

Jim Grant, the executive director of the United Nations Children's Fund (UNICEF) has died at the age of 73. I was very impressed with the talk he gave at the 1985 IPPNW congress in Budapest when he expressed concern about all the children who were dying of easily preventable diseases, mainly diarrhea dehydration. Just a tiny fraction of the money that was then being spent on the nuclear arms race, he said, could have saved the lives of these children. It's still a problem in many parts of the world, but thanks to Jim Grant, a remedy known as ORT, is now saving the lives of about a million children every year. Some introductory words he wrote in a 1993 report for UNICEF could well be used as a mission statement for IHA (the italics are mine):

We look forward to the day ... when the progress of nations will be judged not by their military or economic strength, nor by the splendour of their capital cities and buildings, but by the well-being of their peoples: by their levels of health, nutrition, and education; by their opportunities to earn a fair reward for their labours; by their ability to participate in the decisions that affect their lives; by the respect that is shown for their civic and political liberties; by the provision that is made for those who are vulnerable and disadvantaged; and by the protection that is afforded to the growing minds and bodies of their children.

