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Newsletter of  
International  
Integrated  
Health Assoc.

# IIHA NEWS

Summer 1997



## LOTTERY BLUES

We spent many months preparing our proposals for a Lottery International Grant. Some of us worked over Christmas on this. Finally the grant was accepted for assessment and the district assessor came to see us. She was impressed, and obtained some further information to present to the Lottery Board.

"It's in the bag!" someone said.

We were optimistic. In this business you have to cling onto your optimism. Others are so dependent on you and you feel so helpless. You've got nothing very much but your optimism to keep you going.

But on 19 May we received a letter from the Lottery Board saying that they had received 755 applications asking for more than £182 million. The board had £25 million to allocate for this grant round and therefore "has had to make

some difficult choices about which projects should receive a grant." There was no explanation why we were turned down. There was no time to explain. They had to get ready for the next round and prepare information about funding priorities, new application procedures, and so on. Bureaucratic concerns came before promoting good relations with the Charities that had worked so hard on the applications.

### I am sorry to have to tell you....

When I opened the letter from Gerald Oppenheimer, Director of UK and Corporate Planning and read "I am sorry to have to tell you...." I thought of Olga and Yaraslavi of Lviv, N.W. Ukraine, who have a child of 14 months with CF, and have started a parents' group to raise funds to buy medicines. And Sergei in Kiev, who also has a child with CF and is president of another parents group. In spite of opposition in their own country, they are campaigning for home help, for the creation of a National CF Association and the training of doctors who are lacking in expertise in diagnosing and treating cystic fibrosis.

The *Daily Mail* complained about the Lottery spending money abroad. They quoted an anonymous MP who said: "Charity should begin at home before going abroad." The charities supported by the Lottery included *Save the Children Fund* and *Wateraid*, who help children everywhere, including many who are dying in their thousands for want of clean water! I wonder hasn't anybody told the *Daily Mail* that it's one world and that children are children wherever they live?

In Britain we spend £12,000 a year on the treatment of a child with cystic fibrosis. No-one is complaining that they should not receive the best treatment available, but some routine treatments are very expensive and are not really necessary in all cases. But in Lviv and Kiev, in the Ukraine, there are no medicines available, not even the essential ones, such as pancreatic enzymes, that save children's lives, unless you can afford to buy them. We have found in Moscow that for the equivalent of £1,000 a year the health of a CF child and the quality of her life will improve tremendously. IHA has achieved a lot for a relatively small investment.



Natasha has CF and depends on help from IHA

We would like to do the same in the Ukraine, but there are medico-political as well as financial restraints that make our work very difficult.

### Work in Odessa

During the past 18 months we have been working in Odessa where 90 per cent of the children who attend the University Hospital Clinic are getting better and growing normally and a parents support group has been established. Our work there has been financed by the European Commission Tacis/LIEN Programme whose monitors visited the centre last September and wrote a very good report about our CF project. It was noted, however that "the local partner is less convinced than IHA about the importance of developing a support group for parents of children with chronic illnesses. However, the project achieved an objective not originally specified which is the improvement in the mother's morale, which occurs automatically when the health of her child improves."

The European Commission task manager wrote to IHA congratulating us on the fact that "no major problems were found by the monitors." She added: "You may believe me that this is not always the case."

Our problem now is to extend this work to other regions and to concentrate more on establishing support groups in the main cities. Social infrastructures are weak in all the countries of the former

Soviet Union, so that the idea of self-help and of parents groups helping one another with the



Dorothea astride a Kiev street lion

encouragement and backing of the government, and of voluntary work generally, including fund raising, are little understood. There are few professionals in social welfare.

There is also intense rivalry between doctors who, in a hierarchical health system, are intent on building medical bases where they have a monopoly of expertise which they are reluctant to share with others.



### New project

We were asked by the European Tacis/LIEN Programme to apply for funds for a new project. But we have problems in dealing with people who have been brought up without any notion of co-operation and we are finding opposition from some members of the medical profession, though not from the parents groups. We find that besides trying to help the children we are also involved in what could be called conflict resolution.

### Afraid to talk

Some doctors are afraid to talk to us about CF for fear of treading on another doctor's toes, and one consultant we met was deprived of one of her jobs because she had agreed to help a parent to establish a centre for CF children. It's all very tiresome and unpleasant at times, but we have a lot of support from some friends in Russia and the Ukraine who are quietly helping us and from the European Commission who have been very helpful. It's strange how difficult it can be sometimes to help people who need help but are, understandably, too proud to acknowledge it. And, apart from that, they do not believe we are working voluntarily. They see us as competitors from abroad.

### Difficult relationships

We have overcome most of these problems in our dealings with the Republican Children's Hospital in

Moscow, where we enjoy very close and friendly relationships with the paediatricians there, but things are still difficult in the Ukraine. We need substantial funds to carry on. We can't run away from this situation. We started something which has turned out to be more difficult than we anticipated, but we have received high praise for our work so far, and we've simply got to go doing all we can to help the children with CF and their families

Roy Ridgway

## Preconception planning for healthy babies

by Simon House

Bringing healthy children into the world through parental care and planning before and after conception - that has long been Roy Ridgway's dream, and mine. In fact it was that dream that brought us together in the first place. Now we have a practical plan to make this possible - at least in the Ukraine. We are very slow here in Britain to latch on to what may be the most important step we can take in protecting the health of future generations.



### Partnerships

It was on St Valentine's Day this year, when I was in Kiev, that we took an important step in establishing a programme of reproductive health care, involving pre-conception care. I had discussions with the Ukraine Family Planning Services and MAMA 86, the former a department of a leading paediatric research institute and the latter a woman's charity concerned mainly with environmental problems affecting women's health in particular. The discussions were about establishing partnerships between ourselves and the Ukrainian medical and voluntary services.



Professors Lukyanova and Vovk

It was earlier, while visiting Kiev in June 95, that I first met Professor Irena Vovk, head of *Family Planning in the Ukraine*, and Dr Larisa Novik, the head of a service called *Mother and Baby Care*. Irena and Larisa had both been to Britain for training. Both were enthusiastic about our reproductive health care project, which we have called *Health of Future Generations*.



Olga and Nina



Anna



Ludmilla

An important part of IIHA's mission is to promote the integration of the different services offered by different government departments such as those for the environment, the social services, education. Each has its part to play in the health of a nation.

#### **MAMA 86**

The woman's environmental group Mama 86 recalls in its title the disastrous year that marked the beginning of the global concern for our deteriorating environment. A phoenix rising from the ashes of Chernobyl, MAMA 86 is particularly concerned about safeguarding parental and child health. As a charity in the former Soviet Union it is still something of a rarity.

I had first met members of MAMA 86 in London when they were visiting their partners, the Women's Environment Group (WEN), which Roy had contacted at the time when both they and IIHA were applying for funding to the European Union. We were

both successful and complemented each other in our work in the Ukraine, especially in the IIHA project *Health of Future Generations*.

MAMA is extending its work from city to city in the Ukraine, and at the same time is operating on an international network. Their director is 27-year-old Anna Syomina. Tall and thin with a beret and curly quiff, she seems to have stepped straight out of the twenties. She sweeps around the office dealing with several things all at once, and has an opinion about everything. Her office walls are covered with publicity, designs and cartoonish sculptures. Two computers rattle, two telephones ring continually, while Anna's cheerful team brim with vitality as they attend to the detail work connected with their projects.

Maxime, who speaks English, runs Hotline, an information service and focus of

the European Union LIEN grant. Ludmilla, Nina and young Oksana, are lively hostesses, who struggle valiantly with their English.

To increase awareness of the many environmental hazards affecting the health of women, particularly reproductive health, MAMA 86 has established healthy parenting groups in various regions, with contacts in several cities, including Lviv and Donietsk. They also have an EC TACIS grant shared with the Women's Environmental Network and Healthy Planet, Holland. With such common aims and outlook, it seems we could co-operate effectively.

#### **Old Kiev**

One minute's walk from MAMA 86's office is their apartment, typical of old Kiev, sparsely furnished but spacious and chandeliered. On two occasions it was to become our home. The MAMA group have already been a great help to us, allowing us to use their office equipment

Apart from the dominating threat of Chernobyl, which is only sixty miles from Kiev, and other serious pollution problems, Ukraine has been suffering worse poverty than Russia. It is said that two out of three people don't get enough to eat, and, sadly, this is especially true of the young. Most people can't afford meat, and, in winter, fruit and even vegetables become too expensive for most families. You seldom see greens.

It is scarcely surprising that over 10 years the birth rate has dropped from 33,000 to 20,000. According to official statistics, the number of abortions (the main means of contraception) in a year amount to 68,000 but this figure is generally feared to be much higher.

There has recently been a serious increase in low birth weight babies, implying malnutrition or pollution, with a higher risk of congenital disorders.

But merely giving advice on nutrition seems of little use to people who can't afford to eat good food.

### Family planning programme

To contend with the terrible rate of abortion, particularly among teenagers, Irena Vovk embarked on a new Government programme, setting up family planning centres to cover the 25 main cities in the Ukraine. The centres which work with young couples and adolescents have introduced a programme on teenage pregnancy and are also helping with sex education in schools.

In 1993 there were 40,000 teenage abortions a year. This went down to 24,000 in 1995 and is now probably halved, mainly as a result of Irena's work. She noticed that in London there was combined counselling for boys and girls, and she is hoping to do the same in the Ukraine. When

she heard about preconception nutrition she was at once eager to include it in her programme. She saw the sense of distributing nutrition supplements with contraceptives and including this way of tackling reproductive health problems in the literature on family planning.

It is appreciated that contraception can be used not only to reduce unwanted babies and abortions, but to delay conception until the parents are ready for it - that is to say, when they are healthy and well nourished, and consequently able to throw off some of the worst effects of pollution.



## IIHA Planning for Parenthood

The IIHA partnerships plan is for the Ukrainian NGOs, together with the Institute of Paediatrics Family Planning Dept, which was set up in 1994, to focus on:

1. Parents who are planning to start a family and who are receptive to advice on reproductive health care.

2. Children at an impressionable age, who would benefit from advice on sex and pre-conception care.

The project will help people to achieve healthy pregnancies and healthy babies through increasing awareness of nutritional and environmental needs. Information will be disseminated about chemicals commonly used in the factory and home that are hazardous to both partners preparing for parenthood.

We will make available, where necessary, contraception and nutrition supplements, co-ordinating these to provide the best possible foundation for healthy lifestyles. The project is designed to influence national policy and to achieve sustainability in two years.

**'Healthy babies begin before you're pregnant'**  
NATIONAL  
CHILDBIRTH TRUST  
PAMPHLET

### MOSCOW HEART SURGEONS LEARN NEW TECHNIQUES IN SOUTHAMPTON

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

To help remedy this, a Russian surgical team from the Moniki Institute, a general hospital in Moscow about the size of the Southampton General Hospital, visited the Wessex Cardiothoracic Centre for a week in June to learn new approaches and skills in children's heart surgery.



(l-r): Dr Mikhail Martakov; Prof. Selivanenko; Dr Galina Orlova; Dr Mikhail Roudenko; and Sister Lyubov Louniakina

This is the first of a number of exchange visits that are planned by IJHA. The problems to be addressed are:

- expertise in complex heart surgery in infants and management of post-operative care
- improvement in the management of children

with complex heart problems; and

- training in the multi-disciplinary approach to child health care.

The project should help to improve the quality of life of many children and reduce the number of operations performed on a child with a complex heart problem.

The Russians will also learn about the many "quality of life" measures that assess the impact of different surgical procedures on the child and his/her family.

In contrast to the Russian doctor-centred approach to child

health care, the development of the multi-disciplinary team for decision making and management in the UK has led to a child-centred approach.

Members of the Moscow team were all impressed by the way the Wessex team got together to discuss the patient's condition and arrive at a consensus on operating procedure.



Dr Tony Salmon, Wessex Cardiothoracic Centre host

The hierarchical system in Moscow does not allow for such discussions. The surgeon's methods are never questioned.

Professor Vilor Selivanenko, the leader of the Moscow team, said: 'What impressed me most was the informal way in which diagnostic and procedural problems were discussed. All of the team bear the responsibility of the operation, not just the surgeon.'

The Wessex team is going to Moscow later this year, where they hope to perform operations on Russian children. The long-term aim is to develop an outreach programme in Moscow where children and their families participate in the post-operative or on-going care of children with heart disorders.

IJHA hopes to get some support for the Russian charity, the *Society for the Care of Children for Cardiovascular Diseases*, which is run by a very dynamic health worker, Vera Basis, who is the mother of a child who had a heart disorder, but is now fully recovered and helping her mum run the charity. This sort of thing rarely happens in Russia and must be encouraged.

## Disaster area in North Caucasus

A letter from Fatima Dzutseva appeals to IIHA to help the people in her region of the North Caucasus, where, she says, there is a big increase in the morbidity and mortality rates of children. She offers to open an IIHA branch in the region. The North Ossetian Alanian department for health care has written to IIHA welcoming the idea.

An epidemic of tuberculosis is causing most anxiety among the health authorities.

"There are a lot of children living in single rooms with their families," says Fatima, "where there is often an adult suffering from TB."



A thin mist hangs over the whole area which is extremely polluted. This is regarded as the main cause of an increase in birth defects and such diseases as TB and cerebral palsy in children.

"If an organization such as yours could somehow ease the situation, I would be happy to become involved. My own attempts to have children have been a failure," she says, "so I might be helping myself as well as many other couples by helping you."

Fatima teaches English at the University of Vadikavkaz, where all students are required to take a year's course in nursing.

We have written to her recommending that she should establish a local charity with which we might form a partnership. We would welcome suggestions from readers, including volunteers who could visit Fatima on a fact finding mission. IIHA could organise this but have no funds to cover expenses.



## IIHA helps organise Czech conference to improve human rights of disabled people

IIHA was invited by the European Union PHARE Programme and the Czech Republic's Ministry of Labour and Social Affairs (MOLSA) to play a leading role in organising a conference in Prague on the human rights of disabled people.

IIHA collaborated with EPOS, the German health consultants, in bringing together experts from Britain, Germany, France and Sweden at the Atlantic Hotel in Prague on February 17 to 18.

In a welcoming address, Marie Kudovla, director of the social policy department of MOLSA, said that the Czech Republic wanted to protect the rights of disabled citizens and, as a potential member of the EU, to find solutions which harmonized with those of other European countries.

One of the main findings was the need in the Czech Republic, as in other Central and Eastern European countries, to strengthen (if not create) the *civil society* - i.e. the NGOs, agencies, self-help groups, lobby groups etc. which form an essential part of the European welfare state. In the past such organisations were discouraged or even forbidden and the actual number of such organisations and the extent of their activities are relatively modest.

The report of the conference stated: "It would seem best for the Czech public authorities to develop their relationship with voluntary organisations and eventually even to subsidise their

activities where they are providing an appropriate response to the needs of the disabled.

IIHA was glad of the opportunity to study the legal aspects of this problem, which is not recognised in some Eastern European countries, and makes it difficult sometimes for us to help people who are socially disadvantaged by chronic illness or other disabilities in Russia and the Ukraine.

IIHA is now exploring the possibility of holding a similar conference in Moscow with a view to obtaining government recognition and backing for the social aspects of our work with children and families disadvantaged by illness.

It was stressed in the conference that there was no "best solution" in any country and there is no model which could serve as an absolute reference point. Certain principles, however, were agreed including:

- the duty of the state to provide a normal place in society for disabled persons;
- the provision of medical, vocational and social rehabilitation to all persons in need of such services;
- the duty to provide rehabilitation as a continuing process, beginning with the illness or accident and lasting until the achievement of social integration;
- special encouragement should be given to private organizations, self-help groups and "lobbyists" for the disabled. Such activities should be recognised and assisted by public authorities;
- steps should be taken for the co-ordination of the various medical, vocational and social services as well as of private services in order to ensure both efficient aid to disabled persons and their integration into society.

A paper on English law on discrimination was presented by Dr Richard Light, an expoliceman living in Romsey, Hampshire, who, after a serious accident which left him permanently disabled, became qualified as a lawyer specialising in the rights of the disabled.

The moderator was Mr Anthony Wolstenholme and the rapporteur Mr Alan Massam, both of IIHA.

Since the conference Richard Light has been invited by the Czech Ministry of Labour and Social Affairs to run a three-day seminar on framing laws to prevent discrimination of disabled people. He has also agreed to be a consultant in IIHA's plans to organise a conference in Moscow similar to the one in Prague, but with special emphasis on children who are socially disadvantaged through illness.



## KNOW HOW (HSPS) OFFERS FURTHER HELP TO IIHA

The Know How Healthcare Small Partnerships Scheme (which is a Foreign and Commonwealth Office initiative) is offering further help to IIHA for the development of "outreach" work in Moscow and the twinning of regional CF centres in Russia with centres in Wessex.

At a meeting in the CAF Centre in Southampton Row, London, in March attended by Roy Ridgway of IIHA, Julia South, board member of HSPS and Christine Forrester, the hard-working manager of the scheme, IIHA was congratulated on the work of the Moscow/Southampton Cystic Fibrosis project. Julia South, an expert on social welfare work, said that members of the Board's evaluation team were

extremely impressed with what IIHA had accomplished in Moscow both on the clinical side and on the outreach side, including the development of the parents support group, which had become an effective pressure group under Alexander Zashkov.

In particular, the team had been impressed with the way Dr Chris Rolles and his team had worked closely with Professor Nikolai Kapranov, to improve the quality of clinical care of CF patients. Ms South said that the rapport between the Moscow and Southampton teams was remarkable.

She said that most people she met emphasised that "Roy Ridgway" was the catalyst. She saw IIHA as an umbrella group, looking after all the different groups and bringing them together in an holistic approach, which would include community-based care and attention to environmental factors.

Christine Forrester said that the evaluation team, who had met Professor Kapranov and his team, and had visited Alexander Zashkov in his office, were very satisfied with the work that had been achieved so far. On the outreach work they recommended that the Know How Fund Healthcare Small Partnerships Scheme (HSPS) should try to support further work on community outreach and the development of family support.

It was agreed that the funding for another nurse to visit the UK could be used for Judi Madison and a small grant of £500 for the IIHA to enable the proposal to be developed in full consultation with our Russian partners.

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### MISSION STATEMENT

IIHA promotes a community-based system of health care which puts the patient first and focuses on the health of families in their physical, social and educational environments, with a particular concern for those who are socially disadvantaged through chronic illness or disability. In carrying out its objectives, IIHA seeks to bring together all those involved in the material, mental, spiritual and social well-being of men, women and children, including international agencies, national and local government departments, voluntary organisations, religious bodies, business and commerce.

HEALTH IS A STATE OF COMPLETE PHYSICAL, MENTAL AND SOCIAL WELL-BEING: IT IS A FUNDAMENTAL HUMAN RIGHT AND AN IMPORTANT WORLD-WIDE SOCIAL GOAL.  
WHO 1978