

Child Health International



Formerly 'International Integrated Health Association'
Spring/Summer 2004



Charity Know How, a major funding organisation, closes - we need your help!

Charity know How provided funding to CHI for nearly 10 years enabling us to carry through more than a dozen projects. In 2003 it closed its doors plunging our planned Belgrade project in to disarray (see page 2 for full report).

As government increasingly sees the charitable sector as a legitimate source of services for our own disadvantaged citizens in the place of State provision so it becomes harder to win funding for overseas projects to help the disadvantaged in other countries. Yet whilst the charitable sector has

grown to meet these needs so individual charitable giving as a percentage of income has dropped.

As a small charity CHI has felt these changes acutely and desperately needs not just your goodwill but your money if it is to survive and continue to help children less fortunate than our own. Whilst we continue to keep our running costs at an absolute minimum, staffed entirely by volunteers, the 'shopping list' to the right indicates the projects we are hoping to realise. Donations, however small really count.

Registered charity no:1014734

Projects 2004

We have received the following requests for help but we can only give help if we have funds to do so. We desperately need donations large or small to continue our work. Please help us and spread the word amongst your friends and acquaintances!

1. Crimea cystic fibrosis exchange cooperation approximately £5,000 per exchange needed
2. Vilnius- Southampton cardiac video link £12,000 needed
3. Egypt - Southampton cardiac exchange cooperation approximately £4,000 per exchange
4. India cystic fibrosis : invitation received to forge links & exchange cooperation in the region of £15,000 needed.
5. Kaunas, Lithuania cystic fibrosis : invitation received to forge links & exchange cooperation £10,000 needed
6. Riga, Latvia cystic fibrosis : invitation received to forge links & exchange cooperation £10,000 needed
7. Sophia, Bulgaria cystic fibrosis : invitation received to forge links & cooperation £10,000 needed
8. Sophia Bulgaria epilepsy : invitation received to forge links & cooperation £10,000 needed

BELGRADE - BUT ONLY JUST!

Following an investigative mission CHI had plans to return with a full team at a budgeted cost of £8,000 --- but the funding body applied to closed down!! After much soul searching and a heavily trimmed down budget, made possible by relying on local families instead of hotels, the trip was able to go ahead paid for out of existing CHI funds at a cost of less than £4,000

So Between 25th and 30th October 2003 Dr.Knight from Firmley Park Hospital, Jackie Hext, clinical Nurse Specialist in Cystic Fibrosis, and Jo Thomas, Physiotherapist visited Belgrade.

Jo Thomas reports....

On Saturday 25th October 2003, a party of us from Firmley Park Hospital, a CF specialist physician, nurse and physiotherapist, left Heathrow on a visit to Belgrade at the invitation of a group of families each with a member diagnosed with Cystic Fibrosis. The flights were sponsored by CHI.

Despite difficulties at Customs we eventually were allowed entry. We were met at the airport by the father of a CF child, and I stayed with the family of a 22 year old girl with CF. The itinerary started with a assessment of about 10 CF sufferers. The next day we went to the Mother and Child Institute, the centre of excellence for



the country in paediatric care, and met the two main physicians, who were very accommodating. We were given the use of the treatment room in the Day Clinic where Dr. Knight inserted long lines, to give IV therapy (we'd brought the drugs with us) to selected patients. The families were taught how to look after these. We witnessed the camaraderie between the friendly and hospitable nurses and the regular long term visitors to this day clinic.

I also managed to meet the doctor in charge of Physiotherapy who spoke English well. She said her physiotherapists were not specialists with chests but did all aspects of physiotherapy. I chose to demonstrate on a boy of 13, Dracon, who had a cheeky grin and was very bright (although small for his age) .He was finishing his course of IV's and was able to walk down the physiotherapy rooms. I was



joined by 8 or 9 physiotherapists, male and female, and not one of them English speaking! The doctor stayed to translate. It seemed that the physiotherapy was more passive than active. I explained that children in England are taught blowing exercises as toddlers and breathing exercises as soon as they are able and this was combined with general posture and encouragement to exercise and do sport as much as possible. I taught ACBT to Dracon and explained in detail the importance of each part of the cycle, that it could be combined with postural drainage. The department doctor was very interested and I left her some literature.

The next day, I attended an outpatient clinic; where the



physician (following discussion with Dr Knight) asked me to review each patients physiotherapy. This was very interesting. Many young adults were still having to attend the children's clinic. I discussed with patients and parents their routines. One young man, a student, was keen to find out about ACBT.

In general, the families of the patients we saw were doing their best and due to the persistence of a few families and the visit of our team were increasing the profile of the disease. Resources were shared throughout all patients but they did get what was available. Pulmozyme, of course, is too expensive, although a few parents had managed to acquire it for their children and were having it everyday. Last visit, Dr. Knight had advocated the use of 7% saline and salbutamol as an alternative mucolytic for these patients and this was now widespread and proving helpful.

It was interesting that the timing of the nebulisers was not explained to those patients in relation to physiotherapy, nor was the cleaning of equipment. Probably a case of assigning responsibility to do this. Those on pulmozyme I discovered did not realise that physiotherapy should be done afterwards and that ideally a different nebuliser is used for this. Parents often bought things by post such as compressors and nebulisers and thus the significance of cleanliness and drying of equipment is not emphasised. I explained this whenever the opportunity arose. Some older patients found the time doing nebulisers too long and often did not like to do them – a perpetual problem, even in the UK. This could have been because of the type of compressor. There appeared to be mainly Pari boy compressors in use by the parents we stayed with.

These are much slower than the later Pari turbo.

I learned a lot from this visit. It proved a good team building episode and I was able to watch several long lines being inserted and became an expert on how IV's are prepared and administered. I cannot draw too many conclusions about the respiratory physiotherapy for these patients, except that someone must have taught them a routine..



Dr.Knight observes crisis management

The management of patients in Belgrade is essentially to treat acute exacerbations rather than monitor the patients carefully and try and prevent them deteriorating. A number of patients were quite obviously in need of intensive treatment but felt, because their own doctors had not told them that this was necessary, that their breathing was 'fine'. In fact some of them had very advanced lung disease and were significantly under nourished. One patients' lung function had deteriorated very significantly since our visit last year and yet because he'd felt well he was reticent to have intravenous antibiotics.

Yet again it was a very worthwhile and interesting insight into the health care of other countries.

Forgotten by the State

Translation from Belgrade Local Paper, 2003

Help for children sick from CF came recently from 'Child Health International', the founders of which are Dorothea and Roy Ridgway. The Late Mr.Ridgway, a journalist involved in health issues, received the Nobel Peace Prize for his humanitarian work. For twelve years, CHI has been collecting funds and providing help for sick children with CF from Eastern Europe. Mrs.Ridgway came to Belgrade accompanied by Dr.Ron Knight, Head of CF unit, Frimley Hospital, London. We would like to point out that Dr. Knight, also brought his team with him, trained in treating CF. At the Institute in Belgrade, Dr.Knight examined twenty patients and seven of them were installed with 'long-line' system containing the drug for a months intravenous therapy. In addition, the team from England also brought the drugs for treatment based on inhalation and pancreatic enzymes called Creon 25000. Dr.Knight gave a professional lecture at the Mother and

Child Health Institute and exchanged opinion with the doctors and staff from the Institute.

"It is a pity that the Institute in Belgrade does not have the physiotherapists, which is of great importance for this illness," said Dr. Knight. "We have bought along our physiotherapists who will demonstrate exercises" Dr.Knight stressed that 50 years ago only 1% of sick persons managed to stay alive for 10 years, while at present, thanks to new drugs and the development of medicine, the patients manage to live for 10,20 and 30 years. Dr.Knight informed us that his oldest patient is 54, and lives in England, the average life is 32 and is getting longer all the time. But, he continued, here in Serbia the problems are funds, and that the patients and hospitals treating CF, should have support from the state.

Odessa Report

by Dr. Stephen

In September 2002 Dorothea Ridgway and I were invited to Odessa, in the Ukraine, by Professor Nicolai Aryayev, Department of Pediatrics, Odessa State Medical School in his capacity as Chairman of the Family Support Association (F.S.A) – a registered N.G.O now incorporating the Cystic Fibrosis Parent Association originally set up by the I.I.H.A in 1994/1995.

The most recent development of the F.S.A has been the inclusion of children suffering from abuse; as we feared and predicted before leaving for Odessa this ill-defined term caused difficulty within the F.S.A between Professor Aryayev and some of his colleagues and also with Dorothea and myself.

After three days of discussion Child Health International (C.H.I) agreed to support those members of F.S.A who were interested in trying to organise help for street children and also a lady – Galina Martunara – in the community who had in fact been caring for street children for over twenty years without any official support from the Odessa City Council: in 2001 she had set up her own N.G.O: 'My Family is My House'.

Between 1993 – 1997 I had been involved with the Relief Fund for Romania (RFFR) in the Bacau area of Moldova on the border with the Ukraine and Moldavia. In 1992 the RFFR had set up a whole health care team to visit about ten remote villages on a regular weekly or fortnightly basis: following the fall of Ceausescu in 1989 virtually all doctors and many nurses and midwives had left the rural health service.

The project proved highly successful and very popular with the villages but in 1995 owing to politics within Romania and the antagonism of the local Director of Health Services in Bacau the RFFR decided to withdraw its ex-patriot personnel, i.e. the nurse coordinator and the doctor but continued with support to a very

small but highly dedicated group of Young Romanians who managed to continue to provide some care and service to the villages. Within eighteen months from such an unpromising beginning, these young Romanians had set up their own N.G.O – Fundatia de Sprijiu Comunitar (Foundation for Community Support) - F.S.C: this has gone from strength to strength expanding and developing over the years. About three years ago a project for the care of Street Children was started.

In March 2003 I returned to Odessa with a proposal from C.H.I that a group of three or four should visit F.S.C in Bacau to study the organisation and day to day working



of the Street Children Project – learning from their success, problems and difficulties. Clearly F.S.C had already been contacted and had readily agreed to help in any way they could. It was felt that the exchange of 'know how' between N.G.O with similar political and historical backgrounds fulfilled the ideals of CHI in the best possible way. My visit however was not straightforward and a conflict arose



between representatives of the F.S.A. It was difficult, perhaps impossible to know whether these disagreements had been resolved and I left Odessa uncertain in my own mind. But I was convinced that all were enthusiastic about the basic proposal to visit F.S.C. in Bacau.

Throughout the summer a seemingly endless stream of e-mails flowed between Winchester / Odessa / Bacau involving passports and visa applications, travel arrangements, the frequent altering of dates for the visit and the final agreement about the composition of the party leaving Odessa. Finally everything fell into place and on November the fifteenth I arrived in Bacau and on the following day met the three representatives from Odessa. Over the next four days an intensive programme of visits and discussions about the problem of street children in Romania had been organised by F.S.C. The visitors from Odessa were quite overwhelmed by the interest and genuine help given to them by the Romanians while the response of F.S.C to the request of C.H.I was beyond our wildest hopes; more could not have been done. How our friends in Odessa respond to the visit remains to be seen. We wait in hope.

Christmas Concert 2003



Instrumentalists from 'The Pilgrims' School. Winchester Young Voices Choir

A delightful candle lit evening of seasonal singing and music making by the talented youngsters of Winchester Young Voices & Pilgrims School in the beautiful chapel at Wolvesey rounded off our year.....a member of the audience recalls.....

It was with great pleasure that I attended the second Christmas concert at Wolvesey Palace, by kind permission of Michael, Bishop of Winchester and Mrs. Lou Scott-Joynt, and organised by Dorothea Ridgway and the team from Winchester's Child Health International.

The audience and performers alike had the great good fortune of a fine, clear and crisp night with stars and moon to light us along the gravelled drive, arriving with light-hearted expectation within the Bishop's home and being made very welcome.

There was great anticipation as we seated ourselves in the beautiful, vaulted ceiled chapel. The children of the choir 'Winchester Young Voices' were to sing for us, their ages range from eight to fifteen, boys and girls, and their choirmaster is Anne George. Sonorous harmonies, sweet solo parts and sustained energised singing: the children gave much of themselves.

After the interval when the audience drank wine and ate delicious mince pies, the concert began this time with young instrumentalists from Pilgrims' School. The boys all played to a very high standard, demonstrating their talents and the fruits of their privileges.

To round off the evening the choir and musicians combined in inviting the audience to sing two carols, firstly O Little Town of Bethlehem and secondly It Came Upon the Midnight Clear. We eagerly joined in with bright trumpets sounding above this joyful concord.

Before we left our seats Chris Rolles wished to speak about the work of Child Health International and to describe the work needing to be done and the results of what has been achieved thus far. All the performers and audience listened to the descriptions of children's hospitals in the former Soviet Union and how CHI has helped bring about not only the transformations of the cystic fibrosis wards themselves but elevated expectations of quality of treatment and quality of life itself for the young sufferers of the disease. Chris praised Dorothea's mighty efforts and invited her to stand so that we might all applaud her to demonstrate our appreciation.

Lucia Brandon Taylor

NEW PROJECTS FOR 2004

Crimea

Our aim is to repeat the successful formula we used in Lviv, Ukraine in 2002.

Project managed by Tony Wolstenholme, we hope to take a small medical team of CF specialists led by Dr Mark Rosenthal of the Royal Brompton Hospital (National Lung Centre) for a week. The objectives are to improve the diagnostic capabilities of medical professionals, thereby preventing irreparable lung damage (the lungs of a child can be irreversibly damaged if CF is not identified within the first 6 months of a baby's life); to share information with parents, professionals & policymakers about effective management of CF cases and to raise general public awareness, eg in schools; and to help local groups of parents to develop an effective network of support groups to help each other care for children with CF, to lobby effectively, and to raise funds locally.

Clinics will be held in 2 centres, probably in the regional capital, Simferopol, and in Sevastopol. About 90 youngsters are registered as CF patients in Crimea but there are probably many undiagnosed cases. A return visit by Crimean specialists and families to this country would be phase 2.

We need sponsorship for this project and any help would be most welcome – and a visit would coincide with the 150th anniversary of the start of the Crimean War. Though this time our mission will be one of peaceful support and could illustrate the much better relations between our countries!

Vilnius

Following on from several successful trips to Vilnius hospital by a surgical paediatric cardiac team from Southampton General Hospital and Ukrainian children also being treated in Southampton we are fundraising for a video link between the two hospitals. The technology is already in use in Southampton enabling "on line realtime" consultations and surgery with other hospitals which also have the technology, anywhere in the world, any time using broad band internet links. The equipment is British supplied and costs in the region of £12,000 to supply, install and provide training on site in its use – less than the cost of only 3 trips by visiting surgeons !!

Egypt

Assiut University hospital has recently been visited by the Southampton paediatric cardiac team and a programme of further biannual visits, training exchanges and surgical involvement is before the Managing Boards of both hospitals. One of our trustees, consultant Marcus Haw, led the team. He is convinced there is much work that can be done and which would be welcomed by his Egyptian colleagues and the Egyptian Authorities. Although much of this can be self financing or paid for by the Egyptian state a little extra financial help is needed to ensure this exciting initiative, which can help so many children to lead normal and useful lives, gets going and keeps going!

For our cardiac team to visit Egypt cost in excess of £2000 per visit just for airfares and charitable funding is needed to cover these. £4,000 per annum

There is also a need for similar video link equipment to that needed in Vilnius. £12,000.

India

Until recently it was thought that Cystic Fibrosis was Caucasian man's disease. Although the incidence is lower in other races there is clear evidence that it exists and because it is often not diagnosed results in early deaths put down to malnutrition, lung disease or infection (in undiagnosed CF sufferers the consequence of lack of appropriate treatment). The known cases may be the tip of the iceberg.

A pioneering doctor in India is struggling against the odds to provide early diagnosis and then appropriate treatment. He needs help to establish regional centres in other parts of this huge country and we are offering to assist as we have successfully done in Eastern Europe over the last 12 years. At the moment funds are needed to investigate this further. £15,000 is the target.

Kaunas, Lithuania

We have been asked to help by a Lithuanian Doctor who is eager for us to run our "Lviv formula" for CF children, families and professionals in Kaunas. £10,000 can make this happen.

Riga, Latvia

Again we have received a request for help on behalf of CF children in this region and we hope to initiate and manage a team visit with a return visit as phase 2.

Sophia, Bulgaria

a need has been brought to our attention in relation to both CF & epilepsy children by one of our medical experts and funds are needed to investigate in this small country of 8m. people.

CF seems a particular problem in the country's Romany population. CF clinics do exist but there is no system of follow through for patients.

Epileptic children are "labelled" following which normal schooling and normal lives are impossible. Very different to the UK. A parent group with 800 members does exist. They need help to organise and lobby successfully

"We look forward to the day..... when the progress of nations will be judged not by their military might 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"

Roy Ridgway
Founder

Mission to Bucharest

Dorothea Ridgway

Dr John Stephen, a retired family doctor with some experience of caring for children in Romania and Dorothea Ridgway, Trustee and co-founder of CHI, were invited by Madeline Goodman, who runs a charity for sick children in Romania, to come and meet Dr.Tomescu, responsible for treatment of CF children in a Bucharest hospital. Our past experience would enable us to suggest what could be done to help in their country. Our visit took place over 5 days in January 2003.

Madeline organized an interpreter, a driver and also accommodation with a family. The flat we stayed in looked out onto hundreds of identical flats with the palace Ceausescu built for himself at the end of the road.

We visited five families with CF children. The youngest couple had little money and a child of two, and were keen for knowledge and information about CF. The general difficulty they all mentioned was the bureaucracy of annual registration with the authorities and getting the appropriate medicines when they were needed. All the parents respected Dr. Tomescu. Creon in theory is available, but usually runs out half way through the month, and in practice has to be paid for.

We took with us, three nebulisers donated by Dr Gary Connett of Southampton Hospital, which were gratefully received.



Following on the successful strategies carried out in Moscow and the Ukraine, we set up a meeting of the parents group - which had fallen into disuse since its establishment in 2000. This group represented the parents of children attending the Hospital Alfred Russescu under Dr.Tomescu' care. In addition parents of children from Hospital Marie Curie (the only other hospital in Bucharest looking after cystic fibrosis) also attended the meeting and it was agreed that the two groups should cooperate together - hopefully!

We suggested ways of fund raising so that parents who could not afford the medicines could be assisted.

What was achieved

1. CF information translated into Romanian, the power of knowledge cannot be underestimated.
2. Information about chest vibrator provided
3. The parents got together to campaign with doctors for the effective treatment of CF children and hopefully shame the Government into a more positive and active role.
4. Parent meetings now take place regularly.
5. CHI remains in regular contact supplying fundraising materials and Cf information.



PAULINE'S HONOUR

To the left we have a photo of our long serving accountant receiving a 'Winchester and Meon Valley Volunteer Award', in honour and appreciation of her 'outstanding contribution to the continuing success of Child Health International.'

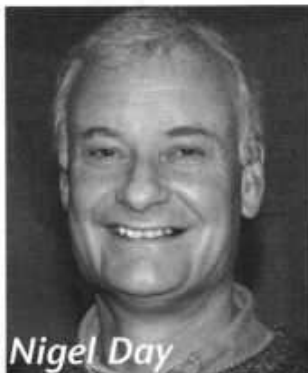
We here at CHI would like to add to this by expressing our gratitude to Pauline who has been with us since 1998, balancing our books and enabling us to continue our work with children around the world.

Pauline is a tireless volunteer and we wish we had more like her! Her other voluntary activities include Meals on Wheels around Eastleigh, working with ex ATS & WRAC members, and Treasurer of The Royal British Legion women's section at Chandlers Ford. Where Pauline finds the time to pursue her passion for gardening is a mystery to us all!



Volunteers

CHI keeps its running costs so low because of all the wonderful and committed volunteers, from Pauline our long serving accountant to all those who stood in December weather to man the table top sale.



Nigel Day

Non practising solicitor joined CHI in Oct 03. Before joining CHI Nigel practiced for over 25 years as a civil litigation lawyer in Bristol, Winchester & Southampton specialising in professional & medical negligence. He joined CHI after meeting Dorothea one evening in July 03 on one of her doorstep fundraising missions. Fortunately for CHI, after taking time out to travel in the Far East & New Zealand, Nigel was

looking for a new challenge and readily responded to Dorothea's gentle persuasion! He comments " I was greatly impressed and moved by the CHI story and its work. I had time on my hands and thought I would just be helping out around the office for a few weeks but Dorothea had much greater plans for me and quickly anointed me Director of Operations!"

Rosemary Kinnaird-Smith Fundraiser.

Retired museum textile conservator. Lives in Winchester and is council member and archivist to the City of Winchester Trust. Heard of CHI through article in the Hampshire Chronicle. Joined CHI December 2003

Colleen Macfarlane

Fundraising coordinator. Joined CHI Dec 2003 is a single parent with two children. Colleen has been busy this past year, setting up a Rock School for disadvantaged children, which looks like it going to be a roaring success. Colleen is also a photographer who exhibits at the Millais Gallery in Southampton.



A snapshot of one of the three successful table top sales of 2003

Mission Statement

CHI, a Winchester based charity, aims to promote in countries without the UK's social and economic infrastructures, a sustainable community based transfer of healthcare knowledge and skills to help children and their families faced with congenital illnesses such as cystic fibrosis and heart disease enabling and empowering these children and their families to receive and their doctors to give the same levels of medical expertise, clinical support and loving care that we take for granted in the UK

Help!!.....Money Desperately Needed!!!

Have the stories in this newsletter touched your heart? Will you back your support for our work with a financial commitment? Do it today, don't put it off!!

To make our projects happen and improve the lot of children and their families far less fortunate than our own,

Our office is manned entirely by enthusiastic volunteers dedicated to making things happen and our project teams give freely of their time and expertise but to run our office and to place teams where they are needed costs money.

Donations large or small, one off or by monthly standing order all make a huge difference.

- If you are a taxpayer the GiftAid scheme enables us to increase the value of your gift to us by claiming the tax you have paid on your donation.

-Monthly, quarterly or even annual Standing orders enable us to budget effectively and plan projects with the confidence of knowing the funding will be available.

-If you work for a company why not ask them to sponsor us or set up a payroll giving scheme for us enabling you and your colleagues to give painlessly as a deduction at source.
- Do have a will? Have you considered a legacy to CHI? Future gifts provided we know of them help us plan for the future and help you reduce the incidence of Inheritance Tax on your estate.

A Donation Form is enclosed with this Newsletter. Don't delay! Complete it and send it to us @

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No stamp necessary.....just address an envelope, put the completed donation form in.... and pop it in the post.....what could be easier?

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