



CHILDREN'S HEARTS

UK Registered Charity 1082929

NEWSLETTER

Autumn/Winter 2001

INTRODUCTION

What is Children's Hearts?

Children's Hearts is a new UK Charity established in October 2000.

Why was Children's Hearts set-up?

to help children born with heart defects in Russia, where disadvantaged and poor children do not have access to the necessary health services.

CHD

A heart defect (abnormality) that is present at birth is known as a congenital heart defect (CHD). Nearly all of these are life threatening. Any baby can be born with a congenital heart defect.

In Russia 1 in 100 babies are born with CHD yet due to the state of the Russian economy only 22% are operated on in time. In the UK, as in many other western countries, this figure is 100% due to the availability of resources.

"At present, surgical interventions on the heart are dramatically vital for more than 6000 children in the Siberian region alone." Prof. A.M. Karaskov, Medical Director of the Research Institute for Circulation Pathology, Novosibirsk.

What are the aims of Children's Hearts?

The aims of Children's Hearts are:

- To identify sick children and compile a list with diagnosis and cost of surgery;
- To supply equipment, disposables and medication;
- To train and supply qualified medical personnel;
- To prepare support information for medical staff and parents about the special needs of children CHD.

Who Works for Children's Hearts?

There is one full-time staff member at Children's Hearts. Amy Cruse is the Director and was herself born with a serious congenital heart condition which was successful repaired at Great Ormond

Street Children's Hospital when she was three-years-old. Since August, Aude Yatchinovsky has been assisting the Director with fund-raising activities amongst others.

The Trustees of the organisation Dr Michael Bermant – Founder and Chair, Mrs Elena Khorishko-Rennie, Dr Dmitrii Strykas and Mr Barnaby Hopson, support Amy in her work.

Children's Hearts Advisory Board

This board contains eminent professionals in the field of paediatric cardiac-surgery and similar charities.

It includes representatives from both Russia and the UK from the following organisations:

Great Ormond St. Hospital; Southampton General Hospital, Bakoulev Cardio-Surgical Centre, Moscow; Research Institute of Circulation Pathology, Novosibirsk; Children's Heart Federation; British Heart Foundation; United Nations Association; Children's Heart Link USA; World Health Organisation; Russian Red Cross Society

Initial Donation from BOSTI

International company BOSTI Trading Limited distributor of medical equipment throughout Russia have generously given Children's Hearts a grant so that they may pay the Director to set up the charity as an organisation and start the fund-raising process for future activities.

This grant has allowed Children's Hearts to obtain office space within the offices of the United Nations Association in London's prestigious Whitehall Court and to put in place a comprehensive profile and fund-raising strategy.



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ACTIVITIES & ACHIEVEMENTS

Children's Heart's Director visits Russia with Founder Dr. Bermant

During the week of 10th February 2001 – 17th February 2001, Amy Cruse, Director of the newly established charity Children's Hearts, went to Russia accompanied by a freelance photographer and journalist.

The visit had two main purposes:

Firstly, to familiarise themselves with the Novosibirsk Research Institute of Circulation Pathology and the Bakoulev Centre for Cardiovascular Surgery, Moscow, their work, their staff, their patients and the problems that the two institutes face in today's economic climate.

Secondly, to handover donated disposable equipment for use at each institute. Children's Hearts received a donation of four oxygenators from the company medical technology company Medtronic. 2 were given to each institute.

On arrival at the Novosibirsk Research Institute for Circulation Pathology (NRICP) we met with Professor Alexander Karaskow MD, Director and Chief cardio-surgeon at NRICP and Yuri N. Gorbatykh MD, Head of the congenital cardiac defects cardio-surgical department.

Amy Cruse and Michael Bermant presented the group with two oxygenators for use by two children in desperate need at the Institute.

These will have saved institute the cost of purchasing and delivering this equipment and more importantly, saved two children's lives.

We watched two surgeons prepare a one-year-old orphan, Sasha Mironov, who weighs just 6kg for an operation to repair his hole-in-the-heart.



He was at NRICP for one week before his operation, in order that he gains the required weight to make him strong enough to undergo surgery.



Yuri Gorbatykh takes over and successfully completes the operation. Sasha is one of the children to use the one of the oxygenators donated by Children's Hearts.

In the room the equipment looks 'home made' and very old even to our inexperienced eye – there were wires over the floors etc. We were all struck by the professionalism of the surgeons and nurses and easy-going nature with which they co-operate with each other in these difficult circumstances and conditions.

We were shown to the Intensive Care Unit (ICU). The ICU is the post-operative unit for children up to three years. The ward contained approximately 12 beds – these seemed quite basic compared with the big expensive incubators typical of UK/USA ICU.

The children we met came from as far away as 2000 km away. Their own doctor's often referred them here to the Institute. The distance from Novosibirsk, and the mode of transport – i.e. some children are too sick to fly can be a crucial factor. Children are usually in hospital for one week before and after the operation in ICU but this depends on seriousness of the operation.



Surgeons in Russia are paid between \$100 and \$250 per month and perform approximately two open-heart operations a day each. Nurses are paid \$30 per month.

On February 14th, we were taken to the headquarters of the Russian Red Cross Society in Moscow to meet with Boris Ionov the first Deputy Chair.

He had received the letter from Children's Hearts asking for his participation in the charity advisory board. He seemed honoured to be asked and accepted the invitation. He then went on to explain about the work of the Russian Red Cross

and the help that he could offer Children's Hearts.

The next day, we were taken to the Bakoulev Institute for Cardiovascular Surgery in Moscow. Where Prof. L.A. Bockeria, the number one cardiac surgeon in Russia had agreed to give us half an hour of his precious time.



The New Building of the Bakoulev Institute.

In the year 2000 the Institute saw 2000 case of congenital heart defects and performed 1280 open-heart operations on children and 315 closed procedures. The institute is a pioneer in Russia in surgery on new-borns. They have an extensive rehabilitation department for babies. 12 operations on children were scheduled for that day.

Prof. Bockeria will undertake as many as 500 surgical cases a year himself. He told us '22% of children in need in this region receive help. That is 22% of registered children – this could be as little as 11 – 15% of the total'. Only 60 –70 % children receive a diagnosis in time. At the Institute there is 5 % mortality rate in general for children.

A full report of the visit can be found in our Annual Report.

Initial Launch of Children's Hearts

Children's Hearts had its first official launch on 31 May '01 from 6-9pm.



The launch took the format of an Art View of Russian paintings at 27 Cork Street. London W1.

We hope that this is the first of a number of arts-related fundraising events for Children's Hearts. The View organised by the "Peace and Colour Gallery" features works by Ilona

Gansovskaya and Igor Tcholaria. "Peace and Colour Gallery" is owned by Irina Emtseva and William Westley-Richards.

We thank them very much for lending their support to this first event for "Children's Hearts". They are kindly giving 10% from sales on the night to Children's Hearts.

We would also like to thank Hy PR for all the hard work they put out into organising the Event.

Current Projects

1. Operations

This project initially identifies 301 children registered with the Novosibirsk Research Institute of Circulation Pathology in Siberia. Each of these children is in desperate need of an operation but necessary resources are not available. We aim to raise funds for their life saving operations.



The project has created a database of these children detailing their specific heart condition, age and more importantly the cost of the surgery that will save their lives.

Since the inception of the charity and this project we have been sent lists of needy children from cardio-surgical centres in other regions and cities of Russia.

- **£500** is enough to give 13-year-old Anastasia a life saving operation to correct the valvular pulmonary stenosis, the narrowing between the pumping chamber of the heart and the artery that carries blood to the lungs. There are **19 children** like her, requiring operations at similar costs on our list.
- **£1000** is enough to give 6-year-old Roman the life-saving operation to repair the hole between the upper chambers of his heart. There are **97 children** like him, requiring operations at similar costs on our list.

2. Equipment

This project identifies specific items of equipment used in the open-heart surgery.

The cost of obtaining these is detailed and the cardio-surgery teams in the individual hospitals will prioritise individual pieces of equipment.

**SURGEON'S TIME IS PROVIDED FREE
OF CHARGE**

3. Training

Having identified the dire need for equipment in cardio-surgical centres in Russia and ways in which Children's Hearts can provide this equipment, The Medical Director of the Novosibirsk Research Institute of Circulation Pathology (NRICP) has identified that, although experts in their field, the Russian surgeons at his institute in many cases need additional training to use the sophisticated equipment. This will allow them to have more successful outcomes when carrying out surgery on patients, specifically very young babies who sometimes require surgery within days of birth. This in turn will lead to reduced need of follow up resources and further surgery.

To meet this need we have arranged with surgeons to have teams of 5 specialists from our partner sites trained at Southampton General Hospital in the UK.

The 5 specialities involved in cardiac surgery are: Cardiology, Anaesthesiology, Perfusion, Surgery, Intensive care.

The purpose of the 5 specialities training at the same time is to ensure cross over and team working. This has been identified as a particular problem in Russian Cardio-surgical Institutes, by Mr Marcus Haw on a recent visit to the Country.

4. Translating support materials.

This project originated as part of a holistic approach to dealing with the issue of congenital heart defects in Russia and focuses on the post-op follow-up. When the operation has been successfully completed and the child leaves the Institute we wanted to be able to carry on providing support, not just immediately after surgery but through out the child's life.

A proposal has been submitted to the National Lottery Charities Board International Grants Programme for this project. We expect to hear if we have been successful in October of this year.

A Big Thank You to..... To the Economist for donating the sum of

£250.00, The Jehangir Manek Anklesaria Charitable Trust for a contribution of £2,800 towards the purchase of an activated clotting machine donated in memory of Mary Stella Winter, Scordis, Papapetrou & Co. and to our individual donors: Dorothy Havergal-Shaw, Geoffrey Monk, Noel de Berry, John Bennett, James Chiavarini and everyone involved in organising the dance night at Madame Jojo's on the 30th of August.

How you can help

- Donations by cash, cheque, standing order, direct debit, covenant
- Gifts of any kind suitable for raffles, auctions, garage/car boot sales
- Attending Children's Hearts receptions, music, art events
- Giving some of your time to help with admin chores and fund raising
- Tell friends, work colleagues, children about the Charity to spread awareness
- Suggest company names which may be able to donate medical equipment, supplies, drugs to provide facilities for CHD surgery and post-operative care
- Join our mailing list of friends to receive regular news of our work and events
- Tell key opinion formers about Children's Hearts and how they can help
- Talk to us about ideas you may have to generate support for Children's Hearts

DONATE TO CHILDREN'S HEARTS SAVE LIVES

I would like to make a project donation of £ _____

I would like to make a regular donation.

Name of your Bank: _____

Your account number: _____

Your sort code: _____

Please pay Children's Hearts _____

Starting on (date) _____ until further notice

YOUR SIGNATURE

For bank Use: Children's Hearts, The Co-operative Bank, Sort Code: 08-92-99, A/c 650 643 24.