



# CHILDREN'S HEARTS

UK Registered Charity 1082929

## NEWSLETTER

Spring/Summer 2002



### Lives Saved!

CH provided funds for operations for four children from Nizhnii Novgorod Region, Operations were performed at Nizhnii Novgorod Children's Cardio Centre.

CH contributed funds for purchasing equipment to provide support for four most difficult cases operated at Bakoulev Cardiac Centre in Moscow

### Report on Children's Hearts first training session at Southampton General Hospital.

In August 2001 Children's Hearts organised its first training session for Russian heart specialists in the UK.

Specialists from the Research Institute of Circulation Pathology (RICP), Novosibirsk, Siberia, Drs Sinelnikov, Strunin, Kornilov and Nartsisova, representing four of the five main specialities in heart surgery, visited Southampton General Hospital's Wessex Cardiac unit for a one month observation and training programme under the supervision of Mr Marcus Haw and his team.

In a letter to Children's Hearts Director Prof A. M. Karaskov, Director and Head Cardiac Surgeon of RICP wrote:

*' Visiting the hospital's operating rooms, ICUs, catheterisation department, Non-invasive diagnostic department and paediatric wards has enabled us to gain experience in using various surgical techniques, managing intraoperative and postoperative treatment, diagnosing cardiac diseases and evaluating surgical treatment outcomes'*

### Advisors Meeting

December 2001 saw the first meeting of the Children's Hearts Advisory Board.



Children's Hearts Founder Dr Michael Bermant and Prof. A.M. Karaskov (pictured left) and Mr Y. Zozulya from RICP came from Russia to attend the meeting.

The meeting was a success, despite the relatively small turn out, many suggestions and action points were made which will form the basis of the work programme over the next year.

### Training at Great Ormond Street Hospital (GOSH)



At the end of January 2002 Children's Hearts arranged for Cardiologist Sofia Kroupianko and Perfusionist Dmitrii Lisitsin from the Bakoulev Scientific Centre for Cardiovascular Surgery (SCCS) in Moscow to visit Great Ormond Street Hospital (GOSH) in London for a two-week training/

observation session.

Reporting on her training session Dr Sofia Kroupianko writes:

*'We visited all units from the outpatient department to the intensive care unit. For the first time I have seen this ideal attitude to children and their parents that we try to develop in our country, based on respect, trust, and open-heartedness.*

*I would like to express once more my gratitude towards the Children's Hearts Fund, personally to Michael Bermant and Amy Cruse for the unique opportunity to witness European cardiologists working methods from within, to "plunge" into the working atmosphere of the Hospital where patients prevail over anything else.'*

### Equipment presented to Perm Institute of the Heart

In October 2001 Children's Hearts received a donation for £2800 from the Jehangir Manek Anklesaria Charitable Trust – The donation paid for an Activated Clotting Time (ACT) Monitor, a piece of equipment which monitors the effects of drugs such as Heparin on blood clotting time. The monitor which was bought in memory of Mary Stella Winter and has a commemorative plaque placed on it, was presented to Professor Sergey Sukhanov (pictured above right) the



Director of the Perm Institute of the Heart by Children's Hearts Advisor Dr Pavel Shafranovsky (left) in January of this year.

## Publicity materials produced



An information leaflet about Children's Hearts has been produced – copies are available from the office for distribution to interested parties.

## GOSH 150<sup>th</sup> Birthday Celebrations.

*Children's Hearts Director, Amy Cruse recounts her involvement in the day*

As a result of the specialists from the Bakoulev SCCS visiting GOSH in January (see above) I discovered that the Hospital was celebrating its 150<sup>th</sup> Birthday on 14<sup>th</sup> February 2002 and were seeking ex-patients to talk about their experiences.

Having contacted the Press Office and explained that I was an ex-patient of GOSH and that Children's Hearts the charity that I run has arranged for Russian surgeons to train at the hospital recently and will continue to do so in the future, they were interested enough to invite me to press briefings and the other high profile and very grand celebrations they had planned for the day including a service at St Paul's Cathedral and lunch at the Guildhall.



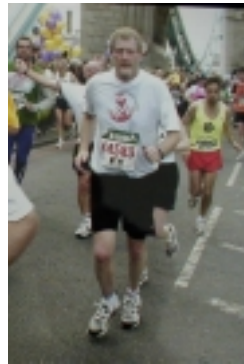
It was a wonderful day – there were about 5 other 'case studies' as we were known who were there to talk about our experiences and memories of the

hospital. Despite the focus of the day being on the hospital, that being the reason I was there, I wore my Children's Hearts badge and talked about the charity as much as possible. Unfortunately despite shaking Tony Blair's hand I was unable to get him to fund paediatric cardiac surgery in Russia – he seemed a little preoccupied!

Through the Press Office at GOSH and with particular thanks to Marcella McEvoy, I was interviewed for Women's Hour on Radio 4, although only aired for about 30 seconds, appeared briefly on the BBC Breakfast News on BBC 1 and along with Child of Courage Jasper, who had had nine brain operations, appeared on Open House with Gloria Huniford on Channel 5!

Picture shows GOSH 'case studies' (from left to right) Amy Cruse, Vanessa Benson, Katie Burrell, Emily Benson

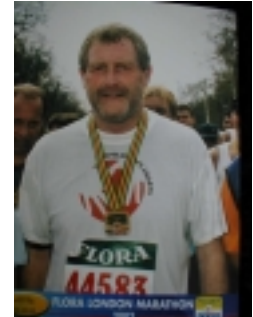
## Children's Hearts enters the London Marathon 2002



At very short notice Sean Stringer kindly offered to run his fifth London Marathon on behalf of Children's Hearts.

He completed the 26 Mile course through central London in just over 4 and a half hours.....

*"I have run 6 marathons, 5 of them the London Marathon and one in Paris. The first one was in London in 1988 which took me 3hours 45minutes. Its been 'down hill' since then with this years time 4hours 44minutes. The extra hour was not spent signing autographs, sadly, but I did beat Frank 'you know what I mean Harry' Bruno and not many people can say that !!"*



Very impressive, well done Sean!

Sponsorship money collected totals over £700.

## Glenfield Hospital on Board

In May of this year the Director travelled to Leicester to meet Mr Richard Firmin, paediatric cardiac surgeon at Glenfield Hospital.

The purpose of the visit was to secure an agreement that Russian surgeons may train there in the future.

Glenfield Hospital is one of only 5 children's heart units that perform surgery using the ECMO technique.

**The ECMO Centre at Glenfield Hospital** – by Heart Link a charity formed in 1981 to provide a vital role in parental support to parents of children with congenital heart conditions at Glenfield

**Extra Corporeal Membrane Oxygenation (ECMO)** is a modern invasive life-support technique which can be used in patients with severe respiratory (lungs) and cardiac (heart) failure.

In 1989 this technique was not used in Great Britain. The general belief among leading British specialists was that there was no place for ECMO in this country. In spite of this Mr R K Firmin, Consultant Cardiothoracic Surgeon, decided to introduce it to the Groby Road Hospital.

The treatment is expensive, labour intensive and financial support from the NHS was out of the question due to the previously mentioned attitude of British experts.

Mr Firmin and Dr Sosnowski learned the technique on visiting the University of Michigan where Prof. Bartlett, the father of ECMO, had developed the leading ECMO Centre.

Mr Firmin approached Heart link to support the introduction of an ECMO programme.

Since November 1998 the Heart Link ECMO Centre (this is the official name of the ECMO programme) has treated numerous patients, not only babies but older children and even adults. The Heart link ECMO Centre is now known world-wide as a very successful Unit.

Although, ECMO is now financed by the NHS there is still enormous input from Heart Link by their continued support to help fund the ECMO research programme, fund medical and nursing staff to attend scientific meetings and teaching sessions, plus purchasing new equipment needed to ensure that the highest and most modern standard of care is given to all those patients requiring ECMO treatment.

Many thanks to Graham – Heart Link's web designer, for kindly allowing the reproduction of this information.

**Professor Sir Magdi Yacoub's Charity on board**

Emma Scanlan, Chief Executive of the Chain of Hope, a charity with very similar goals to our own, founded by world famous heart transplant surgeon Prof. Sir Magdi Yacoub, has agreed to be part of the Children's Hearts Advisory team - we welcome her on board.