

## Fundraising

We have had two major fundraising events.



Kim William's splendid run for CHI in the London Marathon in April 2011 raised £4,667. Among other things, the funds raised in the marathon covered the supply of nebulisers to Moldova. Kim says: *An asthma sufferer as a child, I can identify with the panic and extreme discomfort that one can face, fighting to force some air into an ineffective pair of lungs. I remember being rushed to hospital for a nebuliser treatment and being 'knocked' in the chest region to loosen it up.*



Our second fundraising event, a table top sale in Winchester in September, raised £892. Putting on these sales requires a lot of effort, and we thank all the volunteers involved. We must particularly thank Michael Ridgway and his sister Jane.

We would also like to thank the Winchester Rotary Club for their kind donation of £500.

## The team



We have seen several changes in the team since the last newsletter. We are delighted that Rosie Barnes, OBE has joined us as patron. Rosie was previously Chief Executive of the Cystic Fibrosis Trust; and as a very active patron has already taken part in two of our visits. Tony Wolstenholme stood down as chairman but remains a very busy trustee; we owe him huge gratitude for his work over many years, he has

really kept the charity alive. Jim Hopwood is our new chair. Chris Rolles, the doctor involved with CHI since the beginning, is our new president. Dr Julian Legg (Consultant in Paediatric Respiratory Medicine at Southampton), who has already been to Moldova twice for CHI, is our new medical consultant, and also a new trustee. Bill Salmond has taken on the role of Treasurer. Rod Halls has resigned as trustee, but is still a project manager, and Keith Tester has left us. For more trustee details, see <http://www.childhealthinternational.org/docs/trustees.html>

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# Child Health International

Helping children with Cystic Fibrosis live life

## December 2011

## A Word from the Chairman

It is great honour to take over as your chairman. Tony will be a hard act to follow! Thanks to his leadership we have had a very busy year and now have active projects in 5 countries with firm plans to start another in Albania. Return visits have shown that our approach still works – patients are healthier and living longer, parents' groups are stronger and better able to lobby for improved services. Thank you for the support that made all this possible.

In each country we are in direct contact with enthusiastic local medical staff and patients' groups keen to make the best use of any help we can give. Please help us to help them: this work really makes a difference! Donations may be made via the website or to the address below. If you would like to help with fundraising or in some other way, please contact me at [jim@childhealthinternational.org.uk](mailto:jim@childhealthinternational.org.uk) or on 023 8084 5901.

*With best wishes for Christmas and the New Year* Jim Hopwood

## This newsletter



We have had major visits to Moldova, Lithuania and Ukraine since our last newsletter: reports on the inside pages. On the back page: two fundraisers and a few changes to the CHI team. Not in the newsletter: but do see Chris Rolles' video about CF and CHI's role on our website, or search for "CHI ROLLES" on YouTube.

## Donate, Contact Us

If you would like to make a donation to CHI, you can visit our webpage to donate online via PayPal or CAF, or send a cheque payable to Child Health International

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## Moldova



We made our first visit to Moldova in November 2010 visiting the National Centre for Reproductive Health and Medical Genetics and the National Children's Hospital in Chisinau. Our team included Dr Julian Legg (CF consultant, Southampton) and Alicia Lander (physiotherapist, Poole). The visit included presentations, clinical

sessions and meetings with doctors, other medical specialists, parents, child patients; even the British Ambassador.

The visit identified a number of opportunities, including the use of hypertonic saline to improve lung clearance, better guidance on diet and physiotherapy and probable under-diagnosis. Follow-up has included a lecture by Julian Legg at a national conference to raise awareness of CF among paediatricians; the donation of nebulisers so more patients can use saline; and use of the CF Trust Peer Review process in Moldova, mentored by Dr Legg. Dr Oxana Turcu will attend a new course in Nutrition for Cystic Fibrosis at Leeds Metropolitan University next March and see the multi-disciplinary team in action at Southampton General Hospital.

Meanwhile, a well funded team from the German CF Trust has provided improved testing equipment and extensive training to the Moldovan team so our equipment donation there will wind down.

## Lithuania

CHI's Patron Rosie Barnes, OBE, wanted a more active role than that of a typical patron. Project leader Rod Halls could not take up an invitation to attend an annual CF conference in Birstonas, west of Vilnius, on 7th May, so Rosie agreed to go; briefed by Rod and accompanied by Tony Wolstenholme. She presented "*How families can help in the improvement of CF Care*" to the conference.



Family involvement is an important part of CHI's approach to CF care, and Rosie an excellent ambassador for it. CHI was instrumental in reestablishing the Lithuanian Parents' Group in 2008. We were delighted to see it running very strongly under its president Lijana and her husband Rimantas. (They have three children, two with CF).

The visit showed us that CF care is reasonably good in Lithuania; they now have many adult patients. One possible area of improvement is a CF registry. Rosie discussed the benefits of the UK registry, and we are looking at ways to help establish an effective Lithuanian one. Another issue is under-diagnosis; improving this must involve local political work but CHI may be able to give advice.

Rod Halls has just returned from a visit to Lithuania to discuss next steps; you will hear more in the next newsletter.



## Ukraine



We were delighted to be involved with Ukraine once again, after local politics had inhibited follow on to our 2002 project. Our 2011 project began with a visit from Dr Nataliya Rohovyk (young CF physician) and two from Katerina Yavna (Psychologist) to the Royal Brompton Hospital; followed by a larger visit by the RBH team and CHI to Lviv in Western Ukraine. Unfortunately our visit did not include Kiev as originally planned.

Several of the people involved on both sides were the same as in the 2002 project. The visit to Ukraine included discussions, clinical time and a small conference; and our hosts generously arranged recreation with Carpathian mountain village festivities and a trip to the opera. These visits have established excellent working relationships between the teams.

We have seen huge improvements in care in Western Ukraine since 2002. The team approach and the important role of physiotherapists are now well established, and there is better availability of basic drugs. The diet available is quite good, but their teams ought to include a specialist dietician. There is established parent help in The Ukrainian Association of Help to CF Families and DZVIN, an organization of Cystic Fibrosis patients and their parents; we will be helping them to help their patients.

We plan a visit from Lviv to UK in February 2012 for a specialist CF nurse, a physiotherapist and the head of the paediatric intensive care unit.



