

## Did you know?

- ✓ CF was only identified as a condition in the 1930's.
- ✓ It is believed that Frederic Chopin (1810-1847), composer and pianist, had CF.

- ✓ There are both mild and severe forms of CF. 1 in 25 people in Britain is a CF carrier.
- ✓ Indian doctors are currently investigating the use of turmeric and bean sprout enzymes in CF treatment.

## Bravissimo! An evening to remember...

Eighty CHI supporters enjoyed an inspiring concert on 3 May 2008 in the intimate setting of Wolvesey Chapel at the Bishop's Palace in Winchester, by the kind permission of the Bishop of Winchester & Mrs. Scott-Joynt. The exuberant concertmaster and accomplished musician, Adrian Adlam, created a programme which showcased the talents of the young musicians of Winchester College and the Pilgrim's School. We were treated to pieces from Bach, Kreisler, Beethoven, Fauré, Wieniawski and Cole Porter. We were astounded by the talent of the many gifted young musicians, including two solo violinists, Kaz Costello and Christopher Law.



Kaz Costello

We are equally grateful to Paul Provost, who directed the Pilgrim's School Quiristers in a collection of whimsical "Songs from Friday Afternoons." To round off the evening, we thoroughly enjoyed the performance by the Cantores Episcopi, a Close Harmony Group, who gave us an enthusiastic rendition of the Beach Boys, The Beatles and "Goodnight Sweetheart." Our guests enjoyed gourmet canapés kindly donated by Winchester's Chesil Rectory restaurant, and complimentary wine. The concert raised a record profit of £1,471 for CHI. We will be holding another concert in early 2009 and hope to see many of our supporters there. Our concerts are over-subscribed, so please book early to avoid disappointment!

## Other Fundraising Initiatives

CHI depends entirely on the voluntary efforts of many individuals and several organisations to raise money for our projects. We need to generate enough funds each year to maintain and extend our work by focussing on key initiatives. In 2009, we will be making applications to grant giving organisations and developing links with commercial organisations interested in supporting our work. We will also be arranging quality events for our supporters.

We are also grateful to everyone who has supported our Tabletop Sales in Winchester (St. Maurice Couvert, Winchester High Street) by bringing items and making purchases. The next one will take place in Spring 2009. Many thanks to our loyal volunteer and supporter GuanYu Chen and her husband Robin Sanders, who donated their wedding ceremony collection (£126) to CHI!

Articles in this newsletter bear witness to what can be achieved with small amounts of money. CHI is grateful to all donors, volunteers and friends and welcomes fundraising ideas. If you would like to help our fundraising efforts in any way, please contact our Coordinator, Jane Brown ([jane.brown@childhealthinternational.org](mailto:jane.brown@childhealthinternational.org)).

## Keep in touch via our website

The busy year for CHI has been a busy year for our website as well. We have brought a consistent look and navigation to every page, trying to keep it simple but effective for our supporters. Most important, the content is now kept more up to date, as well as providing an archive of our past newsletters. We update the site as our CF projects move forward and will be posting details on the charity's evolving mission and values statements. We will be adding information on how you can help: medical input, project leading, fundraising, donations and more. So, please visit [www.childhealthinternational.org](http://www.childhealthinternational.org) regularly to see how CHI is advancing. Many thanks to Trustee Stephen Todd for his work on the website.

## Contact us!

CHI is grateful for any offers of support. Donations can be made online on our website or by post. We also welcome any comments you may have. If you wish to be taken off our mailing list, please contact us by email or post.

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## Child Health International

Summer 2008

## A word from the Chairman

Welcome to this newsletter, which I hope you find informative. Quite a lot has been going on in the past 18 months! We have projects now running in Belarus, Lithuania, Latvia, India and maybe soon in Estonia. We are deeply indebted to our volunteer medical specialists at Royal Brompton Hospital, London and Southampton General Hospital. We have much fresh "blood" amongst the Trustees and a new part-time paid Coordinator. But we have slashed our overheads – we operate a virtual office, relying heavily on cost-effective electronic communication.



Tony Wolstenholme

I am delighted that we receive some financial support from Solvay Pharmaceuticals, but we still rely heavily on individual donors. Thank you to all who came to our lovely concert in Winchester in May. To all who read this newsletter, can you increase your support in any way? Do you give through Gift Aid? I am convinced that CHI does make a difference wherever it operates. For a modest investment, many more sick children can be correctly diagnosed and their quality of life much improved. The Cystic Fibrosis (CF) service in the UK is amongst the best in the world – and CHI can channel this experience to where it is most needed. We welcome your feedback to our newsletter and encourage you to find out more on our website [www.childhealthinternational.org](http://www.childhealthinternational.org).

## A new Cystic Fibrosis project in Belarus

A CHI volunteer medical team from the Royal Brompton Hospital, London, visited Belarus from 24-28 September 2007. The team consisted of Dr Mark Rosenthal (Consultant in Paediatric Respiratory Medicine), Nicola Collins (CF Physiotherapist), Rivanna Stuhler (CF Dietician) and Tony Wolstenholme (CHI). The aim was to exchange experience between medical professionals in the UK and Belarus in diagnosing and caring for children with CF in order to improve life expectancy and quality of life. The CHI team received a very warm welcome.



Dr. Mark Rosenthal  
and interpreter  
Marina in Minsk

The highlight of the week was a Conference for 120 medical professionals and parents of CF children. Dr Rosenthal emphasised the team approach at RBH – the Consultant, physiotherapist, dietician, specialist nurse and psychologist work together with the patient's family. The Belarus specialists were most impressed with the approach and with the contribution parents can make. Nicola Collins gave a presentation on physiotherapy for the CF child, and with the help of a 15 year old boy, Aleksei, she gave a practical demonstration of the Active Cycle Breathing Technique (ACBT). Physiotherapy techniques in Belarus do not include breathing exercises, so this generated much interest. Thanks to the UK CF Trust, we provided leaflets, and it was noted that we have a Russian translation of the Royal Brompton Hospital's "Guidelines for the Care of Children with CF" on our website.

We worked very closely with Dr. Vladimir Bobrovnichij, who is responsible for overseeing CF care in Belarus. He confirmed that he had 28 child patients. For a population of almost 10 million, there should be some 1,000 patients – so where are the missing 900? In a so-called "box" or cubicle, the CHI team met their first CF patient, Nikita, aged 6, with his mother Olga. Nikita had only been diagnosed with CF at the age of 5. Before this, disseminated TB had been diagnosed. Nikita's care was potentially compromised by incorrect and late diagnosis. Awareness of CF among doctors in Belarus is currently low and neonatal screening has been suspended. The CHI team also had discussions with the Ministry of Health and visited the Scientific Research Institute of Pulmonology and Physiology, where adult CF patients are treated. Since our visit, negotiations have begun with the Ministry of Health to set up a single "CF Centre of Excellence", headed by Dr. Bobrovnichij.

A Belorussian CF physiotherapist, Dr. Tatiana Papij, summed up her view of the week: "This fact that parents could hear about your principles of treating the CF-patient, that they could see the demonstrations of chest physiotherapy and hear about the influence of nutrition on the course of the illness, it was the GREAT result of the Conference! I am infinitely grateful to you and to all the people who participated in this project because it (without any doubt!) will be helpful to our patients."

The second phase of this project took place in April 2008, when CHI funded a trip for Dr. Bobrovnichij to come to the UK as a guest at the Royal Brompton Hospital to view best practice CF care firsthand. Dr. Tatiana Papij accompanied him and spent a week at RBH enhancing her skills in CF-specific physiotherapy. CHI plans a further visit to Belarus early next year to help establish a national network for children with CF. The September 2007 visit was generously funded by Solvay GmbH.

## Making a difference in the Baltic—Latvia

In April 2007, CHI picked up a call for help from the only doctor in Latvia working with children with CF, Dr. Vija Svabe, based in the Children's Hospital in Riga. Dr. Svabe explained that the majority of CF cases in Latvia are going undetected. There are 28 living patients who have been diagnosed with CF, but studies show there should be 200. "We do not have screening," she said. "I would be very happy if you could have any idea how to help my CF patients and especially those who die without diagnosis. It seems that in Latvia CF is my private hobby."



Dr. Connett in Latvia

At the end of February 2008, CHI's medical adviser, Dr. Chris Rolles, and Dr. Gary Connett of Southampton University Hospital, made an exploratory visit to Riga to discover how CHI might answer Dr. Svabe's call. They discovered that the majority of children with CF are presenting with failure to thrive in infancy and are dying of malnutrition or chest infections before diagnosis. Dr. Svabe does not have a medical colleague to share and continue her work, nor does she have the professional back-up of a team of physiotherapists and dieticians. Certain key drugs and equipment required for CF treatment are not consistently available.

Dr. Rolles and Dr. Connett held joint consultations with CF children and their families and met with the Head of the Department of Paediatrics, along with a representative of the Governmental Health Ministry. We believe that Dr. Svabe's work provides an excellent springboard for future development which would rapidly increase the number of children saved from premature death and improve the quality of life for known cases. CHI's role would be to co-ordinate the set-up of a twinning arrangement with Southampton University Hospital and to organize a trip to the UK for Dr. Svabe and a team she nominates.

## The Next Phase in Lithuania—CHI in Action

by CHI Trustee Rod Halls

In 2006, a CHI team visited the CF service at Vilnius University Clinic. In February 2008, my first role as a CHI trustee was to help organise a reciprocal visit by Lithuanian colleagues during a week's programme at the Royal Brompton Hospital (RBH), London. Accompanying Professor Sigita Dumcius, chief CF Physician for children in Lithuania, were Drs. Nomeda Jokubaitiene and Ramunas Leisys, and Mrs Vilma Narkuniene, the mother of a little girl with CF.

The programme, drawn up by Professor Andy Bush and colleagues at RBH, ensured access for our visitors to all aspects of CF care. The extent of teamwork and integration impressed our visitors - integration means the patient is seen by all relevant staff on the same occasion, allowing parents, patients and staff to agree the best way forward. With low life expectancy for CF in Lithuania, there is also no process to manage the important transition from child to adult care, and scarce resources limit the variety of treatment regimes. RBH's comprehensive Clinical Guidelines on the care of children with CF have now been put into practical use by staff in Vilnius.



Prof. Dumcius and his team

Parents and families of CF children want to generate pressure for improvements, so the visit to the CF Trust in Bromley was highly instructive. Mrs Narkuniene, has since become Chairman of Lithuanian CF Association, helping to organise a conference for clinicians and parents in the Autumn of 2008 and compiling a register to improve communication and support.

It was gratifying to see how energetically the Lithuanian team threw itself into learning as much as possible from all the sessions—from clinical practice to organisational issues, public awareness and 'health politics'. It was a rewarding reminder of how, with modest resources, CHI can support continuing improvement in the care for children with CF. A twinning arrangement between RBH and Vilnius University Hospital is planned and Professor Bush has already visited Vilnius again. CHI is bringing a Lithuanian Physiotherapist to the UK in September for a Eurocare CF course and for specialist CF physiotherapy training.

CHI wishes to thank Professor Andy Bush and all who helped the visit to run so smoothly at RBH; and Rosie Barnes, CEO of the UK Cystic Fibrosis Trust who shared her experience with the Lithuanian team.

## More about CHI

CHI was founded in 1992 by Roy and Dorothea Ridgway, whose son, Tony, died from CF. They discovered that medical care of children with CF in many Eastern European countries lagged far behind the UK. They found compassionate medical specialists in Britain keen to share their experience without cost. Since then, CHI has acted as a broker, transferring UK medical expertise abroad. We've had considerable success transforming the CF service in Russia and Ukraine, we've facilitated a step change in India, and we are now making a difference across the Baltic Countries.

CHI works closely with partners in order to make lasting changes to:

- **Early accurate diagnosis:** This is helped by teaching clinics, guidance on changes to medical education and better parental awareness.
- **Prolonging life** through advice on diet and physiotherapy administered by parents.
- **Making medication more accessible** by encouraging Governments and pharmaceutical companies to offer treatment at an appropriate cost.
- Encouraging the formation of **Parent Support Groups**, so parents can share their experiences, offer mutual support, and become advocates in seeking health policy improvements.

## Meet the CHI Team

What do a retired Naval Officer, a former NHS Trust CEO and a retired IBM Executive have in common? We're all Trustees of CHI, volunteering our time and skills for a worthy cause. CHI welcomed **5 new Trustees** in the past 18 months:



**Tony Wolstenholme** (a former naval officer who has a long history with CHI.) Tony took over as Chairman in March 2007. "Working with CHI brings me into contact with several medical professionals working in the field of CF. This is a most heartwarming experience as they work so enthusiastically with our clients and with such evident effect."



**Val Black** (Consultant, Healthcare Education Quality and Regulation): "CHI maximises impact by transferring skills and knowledge to health professionals and families in a targeted, cost efficient way."



**Rod Halls** (former CEO, Winchester & Eastleigh NHS Trust): "Children are dying early because they don't have access to the simple, effective treatment available in the UK. CHI's work changes that. So why wouldn't you support it?"



**Chris Leworthy** (former CEO, St. Martin's Healthcare): "CHI has a common-sense approach to providing long term solutions—not just a quick fix."



**Christine Nicklin** (former Marketing professional): "What impresses me about CHI is how it makes a significant improvement in CF care in a short period of time by focusing on proven low cost, high impact methods."

We continue to enjoy the support of our **ongoing Trustees**:



**Rick Foulsham** (former diplomat and CEO of the charity Hope and Homes for Children): "CHI transforms the quality of CF care in the countries where we work, linking volunteer medical specialists in the UK with their local counterparts."



**Michael Ridgway** (son of the founders of CHI): "What enthuses me about the charity is its sheer potential to help sick children abroad, building on its uniquely successful methods. There is a great need for better medical care for children suffering from CF and we can go a long way to help fulfil those needs with minimal financial investment."



**Stephen Todd** (former IBM Executive and visiting Professor of computing): "CHI impresses because it does two things supremely well: efficient deployment of an effective low cost solution and helping communities to support themselves."

We are grateful for the support of our other **dedicated colleagues**:



**Dorothea Ridgway**, co-founder of CHI, remains our President but has stepped back from responsibilities due to fragile health.



**Jane Brown** (former Charity Director and now CHI's Coordinator): "It's very rewarding to see the huge benefits CHI's work accomplishes at such low cost."



**Chris Rolles** (Medical Consultant to CHI and retired paediatric CF specialist): "Roy and Dorothea Ridgway asked me in 1993 to help counterparts in Moscow. The project was so successful Russia-wide that I have wanted to replicate the model in as many countries as possible."