



Child Health International

Helping children with Cystic Fibrosis live life

2014 Newsletter

A Word from the Chairman

Welcome to our 2014 Newsletter.

The last year has been busy and productive for CHI. We established a relationship with two new UK clinical teams and revived another, doubling our capacity to support partners overseas. We started to work with Abbott Laboratories, successors to Solvay, who provided financial and logistical support to our new project in Bulgaria; and with Ostrova, a Russian charitable foundation supporting CF clinics in the regions of Russia. We began to support adult CF clinics for the first time; the need for this being an encouraging sign that improvements in paediatric care are having an effect. We now have or are about to start active programmes in nine countries, up from five two years ago.

We welcomed three new trustees to the board, Phil Penton, Laura Timms and Katie Toms, considerably lowering our average age and further reducing our gender imbalance. Tony Wolstenholme stood down from the board in April 2013 and as a project manager a year later due to ill health, his persistence and diligence underlie much of the progress detailed above. David Sawyer also left the board after guiding us through the revision of our Articles of Association and Charitable Objects, bringing them into line with current legislation. Rick Foulsham resigned in November after 10 years valuable support and guidance. We wish them all well for the future.

All this has been made possible by the continued support of our donors and volunteers. **Thank you all!** Your support makes a real difference to children and their parents.



Jim Hopwood

If you would like more regular updates on CHI's work (at less cost to us), please send your email address to us: info@childhealthinternational.org

Changing Times



CHI's core values have changed very little over the years: promoting simple and cost effective treatment; especially the role of physiotherapy and diet, and the importance of multidisciplinary teams and self-help parents' associations. Exchange visits are a central part so teams get to know one another;

we can understand the particular circumstances under which our partners have to operate, and they can see how members of UK teams work together. We are currently engaged to various degrees in Albania, Bulgaria, Estonia, Greece, Latvia, Lithuania, Moldova, Russia and Serbia.

However, exchanges are getting more and more complex to organize. We really depend on our project managers; their work is very rewarding but often frustrating, and for every project on the boil there is usually another one stalled but often requiring even more effort. Our NHS teams are under increasing pressure at home which makes it difficult to organize visits. We have had changes to staff from illness or even death which make a big difference to a team's ability to participate, and also visa issues both last year and this year have proved expensive to CHI and time-consuming in organization. So, **a big thank you** to our volunteer project managers and our NHS teams.

On the other hand, communications such as Skype have become much more pervasive. We were able to dispense with the CHI office a few years ago. We now find that in several cases where after our formal exchanges have finished, the clinicians are still in regular contact on general issues and about specific cases. This continued collaboration does not involve CHI directly, but is only possible because of CHI's involvement in the initial exchanges.



Another change for CHI is involvement in Greece in adult cystic fibrosis. We do not expect this to become a long term change in direction, but it can be important because the transfer between pediatric and adult CF care is a problem in several of our partner countries.

Our newsletter does not generally report all that is going on behind the scenes, but it has become an increasingly important part of our work.

Visits

There have been many visits since our last newsletter.

Tony Wolstenholme and our patron Rosie Barnes attended conferences in **Russia** in May 2013 to reestablish links. Chris Rolles was also specially invited to celebrate 20 years since our first projects there, but was sadly



unable to attend. There have been several return visits to UK by Professor Elena Kondratyeva (Director: CF services in Russia); we are exploring further projects.

Jim Hopwood attended a conference in **Serbia** in Nov 2013 resulting in a very successful visit by a young doctor and a physiotherapist to Southampton Children's Hospital this May and we are looking for follow up. One issue is that the rotate physiotherapists between disciplines, making it more difficult to arrange long-running team participation.

Adrian Gamble made a preliminary visit to **Bulgaria** in Nov 2013. Positive initial meetings and atmospherics suggest the situation in Bulgaria lends itself to support from CHI; one of the most promising first trips Julian has been on. The conference was very well attended and the Bulgarian CF community appears well joined up. Return visit has been postponed for various reasons but the project is still active.

A small CHI party visited Riga in **Latvia** this March and we are exploring the most effective themes for future collaboration.

March also saw a visit from **Estonia** to Cardiff; a first project for Katy Toms and a welcome reintroduction to the Cardiff team. We were able to make a return visit this autumn despite late staff changes; most successful with special emphasis on physiotherapy. We are looking forward to a continuing relationship.

CHI has been involved with **Greece** in a slightly different role, for adult CF. The adult CF team at Southampton hosted a visit in April; a return is deferred due to the sad death of a Greek doctor from the Southampton team.

Finally, a team from the Brompton have recently visited Vilnius in **Lithuania**. We have heard it was a successful visit, and await more details.

So, in summary, we are in exciting times with many projects moving ahead.

Events and Fundraising

We thank Katy Toms and Adrian Gamble who have run and ridden to raise well over £1500 for CHI between them.

Looking forward, CHI has arranged a **concert** to be held in the newly refurbished New Hall at Winchester College on **Sunday, 15th March 2015**. Please put this in your diaries; there should be plenty of space in New Hall so let any friends know as well. Adrian Adlam at the college is kindly putting the program together for us; it will include a variety of chamber, choir and orchestral music by young and older musicians. Khachaturian is the only composer name we have now, but these events have always been very enjoyable



in the past so please look on the website for more details on program, time and price. There will be a short talk on CHI's work, and refreshments will be provided with trustees and project managers on hand so you can ask questions or discuss more details.

You can also help by signing up for CHI at Easyfundraising.org.uk, we raised £50 this year through our supporters' use of that site.

Support CHI in your Will, or donate to us

Of course when you make your Will, your first priority will be to provide for your own family. But if you believe, like us, that children and young people with cystic fibrosis deserve special support, please consider what a difference a gift in your Will, no matter how small, could make. We are so grateful to people who choose to support us in this way and give us the ability to extend our work into the future.

If you decide to include a gift to CHI in your Will, or you have any questions about this do contact us. The best way to make or amend a Will is through your solicitor but please contact us if you have any further questions.

To make a donation, visit our webpage to donate via PayPal or CAF, or send a cheque payable to Child Health International. If possible, please download a gift aid form from the web and send it to us.

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