

Child Health International

Helping children with Cystic Fibrosis live life

eNEWS Spring 2016

Welcome to our first e-news. This will replace annual paper newsletters. If you follow our Facebook page you will have seen most items before; apologies for the duplication. If you don't want to receive future issues please let us know at admin@childhealthinternational.org

Laurie Ridgway, grandson of our founders, plans to run the **London Marathon** to raise funds for CHI.

He says "I am well aware of the devastating consequences of suffering from this disease and the necessity of the right treatment, having had an uncle with Cystic Fibrosis. I am so grateful to be free from this condition and that I can take part in the London Marathon. I am at present really enjoying exploring the parks and green spaces as I train."

Please support his efforts here

https://mydonate.bt.com/events/ridgwaymarathon





The 'Russian School of Cystic Fibrosis' took place in Moscow at the end of February. The two day 'master class' was given by a team from the Royal Brompton Hospital sponsored by CHI. It covered the basics of good CF care as practiced in the UK, the benefits of new-born screening, airway clearance techniques, nutrition and the use of pancreatic enzymes, transition from pediatric to adult care and diagnosing and treating difficult cases. Doctors from nine regional centers as well as three Moscow clinics attended. Twelve of them presented cases for review and discussion with the visiting multi-disciplinary team.

And there was time for a little sightseeing afterwards!



Discussing a local case



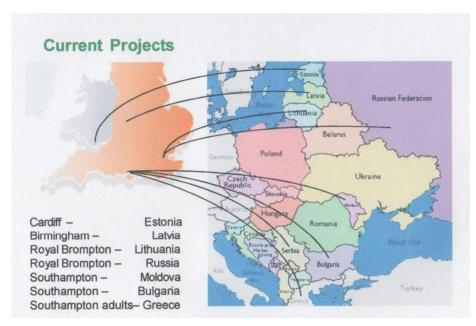
Demonstrating Autogenic Drainage

In October a CF consultant from Birmingham Children's Hospital visited the CF center in **Riga Children's Hospital** and attended the Latvian CF Society conference. A multi-disciplinary team consisting of two doctors, a nurse, a physiotherapist, a nutritionist and a psychologist is in place but lacks specialist skills. We hope to arrange a training visit to Birmingham soon. The conference was an opportunity to exchange ideas with doctors from Russia and the new President of CF Europe as well as local staff and parents.

Specialists in the **Nutrition and Dietetic Group, Leeds Becket University** are working on a CF Nutrition Guide to support parents and doctors in countries where specialist dietary advice is not available. Based on a common core, national versions will include advice on adapting typical local recipes and making best use of low cost traditional foods.







This means we now have six UK CF teams supporting our work. Many thanks to them all!

In March 2015 a 4 person team from Southampton visited the CF clinic in **Varna, Bulgaria**. The local team are enthusiastic but lack expertise in nutrition and lung clearance techniques. Patient records need to be improved. We hope to bring staff to Southampton for training later this year.

Following a number of visits to the Sismanoglio Hospital in Athens and two return visits to the Adult CF unit in Southampton, funded by others, we expect CHI to fund a full multidisciplinary team visit to provide training and mentoring to the new adult team there. As paediatric services improve the issue of transition to adult care is increasingly important in most of the countries where we operate, where there are often no specialist services.

In November we sent a baby/toddler weighing scale and a spirometer to the new **CF out-patients clinic in Chisenau, Moldova**. These will enable them to monitor child growth and lung function regularly and take corrective action before symptoms become severe.





CHI is Recruiting

Due to retirements and moves away from the area we need to recruit:

- Trustees to share overall responsibility for the management of the charity and to ensure expenditure matches our objects and we abide by fundraising standards.
- An 'Hon Sec' / administrator to maintain records and improve our corporate memory.
- Project Managers to maintain good relations with our UK and overseas partners and to arrange and facilitate visits between them.

Meetings are held 4 times a year on a weekday evening; otherwise we all work from home. If you could spare a few hours a month to help a really good cause, or know someone who might be interested, please get in touch.

We now have a Facebook page. For up-to-date news about CHI as it happens, 'Like' this page www.facebook.com/ChildHealthInternational/ (typically you will get one or two short messages a month – you will not be deluged or harassed!)

Our **2014 – 15 Annual Report and Accounts** has been lodged with Companies House and the Charity Commission. Key points are:

- Visits made to five overseas partners and email contact maintained with six more.
- A sound financial position thanks to a generous legacy and delays to some projects.
- Plans developed during the year will lead to increased expenditure in 2015-16.

If you would like a copy please ask.

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