



Child Health International

Helping children with Cystic Fibrosis live life

Autumn 2018



Dr Hazel Evans from Southampton reviews patients with Professor Vevecka in the Mother Teresa Children's Hospital, Tirana, Albania

Welcome to our latest Newsletter

First of all we would like to extend a massive thank you to all our supporters and regular donors to the charity. As the charity is run 100% by volunteers who are not paid, and as the aims of the charity relate almost entirely to "knowhow" the charity can operate on relatively low funding. *But funding is essential!* And we are extremely grateful for all the donations we receive that are vital to the continuing work of the charity. So thank you so much again for so generously supporting us!

As it is a while since our last newsletter we would like to mention that by the beginning of 2018 we completed our most recent projects in **Latvia** and **Estonia**.

Latvia

Professor Brandon Taylor as project manager worked with our partners in Latvia culminating in helping to build a programme to introduce neonatal screening for all newborns in Latvia. It involved Dr Maya Desai and other medical staff at the Birmingham Children's Hospital who very kindly gave their time to host a medical team from Latvia to observe screening techniques and discuss what was needed to introduce them. It was a very successful visit.

The Latvian government has agreed to fund the screening programme but there is a delay in releasing the funds due to a political situation. We believe the delay will be resolved in due course and we will maintain our link with our partners in Latvia in 2019 regarding progress in the establishment of a national neonatal screening programme in Latvia.

Estonia

Following Dr Julian Forton's visit to Estonia we arranged for two teams, each consisting of a paediatrician, a dietician and a physiotherapist from clinics in Tartu and Tallinn, to visit the Children's Hospital for Wales in Cardiff. They observed the multi-disciplinary team in action, spent time with their opposite numbers and attended a satellite clinic in Swansea – an organisational approach which could bring great benefits to patients who do not live near one of the major centres.



The two teams of three visiting from Estonia. From Tartu: Tiia Voor, paediatrician, Karin Tammik, physiotherapist, Siret Saarsalu, dietician. From Tallinn: Karin Puks, paediatrician, Margit Juudas, physiotherapist, Liina Heinvere, dietician.

Bulgaria

Implementing a patient registry

Following an exploratory visit to Bulgaria Dr Julian Legg concluded that the most useful improvement in the treatment of CF in the country at the present time would be the development of a register of CF patients. He arranged to meet Dr Lutz Naehrlich, Director of the European Cystic Fibrosis Society Patient Registry at a CF Europe conference in Sofia.

The outcome is a plan to hold a two day conference in April 2019, probably in Varna, to establish a National Patient Register. The conference will be attended by representatives from all four CF centres in Bulgaria. It will be part funded by Abbott Laboratories and will be facilitated by our team from Southampton Children's Hospital.

A patient register has wide ranging benefits. As an easily accessed resource, it is an invaluable aid in understanding health outcomes in patients nationwide. It aids communication between health workers in different parts of the country and provides a source of important information for decisions on treatment. Perhaps most importantly it encourages regular routine assessments and record keeping. It could be a step change for the treatment of CF in Bulgaria.

We are keen to help other countries build national databases and neonatal screening programmes both of which are fundamental to good practice in the treatment of CF.

Dr Julian Legg became a trustee of CHI back in 2011. He is a paediatric respiratory consultant and head of the paediatric respiratory department at Southampton Children's Hospital, chair of the South and West England Audit and Research Committee and a member of the National Institute for Health and Care Excellence (NICE) working group on Bronchiolitis in Children.

Greece



Maria Sarantari, a physio from Thessaloniki, with Dr. Mary Carroll (third from left) and team in Southampton University Hospital.

CHI fist became involved in Greece in 2014 following a request from the Patient's association in Athens. Following an exploratory visit, Dr Mary Carroll arranged a 3 month training visit to Southampton for Dr Filia Dianantea, the newly appointed head of the adult CF service at the Sismanoglio General Hospital.

Since then the department have appointed an administrator and delegated routine prescribing to family doctors so that Dr Dianantea can spend more time on her specialist role. Danai Chandrinou, a physiotherapist funded by the patients' association visited Southampton General Hospital for three weeks to study the latest practice. Among other things she said that her visit "helped me to understand the significance of keeping records and having a continuously updated overview of the patient's history, which might affect positively patient's performance".

Dr Carol continues to hold a clinic in Athens every couple of months and the new staff have come to Southampton for training. A microbiologist came to Southampton in May to learn how to identify the various infections that affect CF patients and select the most appropriate antibiotics.

In February 2019 Mary and two nurses from Southampton University Hospital will visit Athens for approximately three days, to assist them in the developing a program of patient visits at home, specifically in the setting up of IV systems.

And also in February a CF consultant from Thessaloniki, the other major CF clinic in Greece, is coming to Southampton for three months in preparation for taking over the CF unit there after the forthcoming retirement of the current senior doctor.

Dr Mary Carroll is a consultant in respiratory medicine and became a trustee of the charity in January 2018. She has a strong research background, having helped develop the technique of nasal ventilation, applying it for use in cystic fibrosis. She was involved in the discovery that nebulised heparin thins sputum so making it easier to expel and she is involved in testing new treatments for people with CF. She is an international expert in studies using new molecular techniques to better identify the bacteria that cause lung infections.

The CHI Team



Dr Chris Rolles
President



Jim Hopwood
Chairman



Dr Julian Legg
Trustee



Dr Mary Carroll
Trustee



Adrian Gamble
Project Manager



Paddy O'Grady
Trustee



Michael Ridgway
Trustee

JOIN OUR TEAM?



YOU?

The charity is on the lookout for a new Trustee and Project Manager and would love to hear from you if you or someone you know would be interested in joining our team. Medical or administrative experience and an interest in Eastern European countries could be helpful but is not essential. Mainly we are looking for someone with initiative, enthusiasm and good organisational skills.

Please phone Jim Hopwood on 023 8084 5901 or email - chairman@childhealthinternational.org

CHI is at the cutting edge

CHI is always completely up to date because the UK is in the vanguard for treatment of CF using the most up to date methods and practices. And CHI provides access for doctors and nurses from another country to an immersive experience in the day to day ongoing treatment of CF patients in NHS hospitals in this country. And then of course there is the return visit of doctors and nurses from this country to the other country where they will attend CF clinics and mentor the local specialists.

Information is so available these days especially through the internet but there is nothing like personal contact and hands on experience.

This is CHI's powerful formula for helping raise standards of treatment for children and young adults with CF in other countries where treatment is not yet on a par with the UK.

Bike ride to Paris



Michael and Alex on their way to John O'Groats from Land's End in 2005. The cyclists also included Guanu Chen and they raised just over £4000 for CHI.

Cyclists Michael Ridgway (Trustee) and his cousin Alex Clerke who cycled for the charity between Lands End and John O'Groats in 2005 are inviting anyone else who feels up to the challenge to cycle with them in **May 2019** between the two great capitals London and Paris to raise funds for CHI.

They are taking a low traffic cycle route from London to Newhaven where they take the ferry to Dieppe and then it's along the Avenue Verty to Paris. The cycle route goes along quiet roads and traffic free cycle tracks and there are campsites along the way. A Support Driver will carry supplies and camping equipment.

So have you got a bike and would you like to come too? It will be an unforgettable experience for you and great fun - and a very healthy thing to do! If you can't do the whole trip, you can opt for either the first or second leg of it. That's London to Newhaven or Dieppe to Paris.

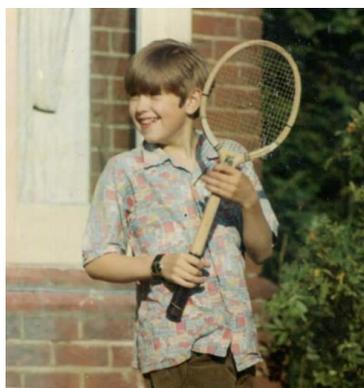
To volunteer to join the trip or obtain more information please phone Jim Hopwood on 023 8084 5902 or email him at chairman@childhealthinternational.org

25th Anniversary

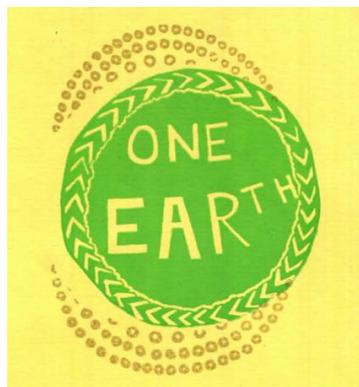
It's 25 Years since our first CF project in 1993.

Our president Dr Chris Rolles who headed the medical team from Southampton University Hospital in 1993 still remembers the initial phone call he got from the charity to ask if his CF department could help with the then dire situation of children in Russia with CF. This was the charity's first CF project that lasted five years and was the basis of our subsequent work in many countries, mainly Eastern Europe but also India and our current project in Greece.

The charity was founded by Roy and Dorothea Ridgway who had a son Tony who had Cystic Fibrosis and who died in 1984 aged 29. Trustee Michael Ridgway, Tony's older brother said they thought of the charity as "Tony's charity".



Tony Ridgway aged 14



A drawing by Tony

A cool way of supporting CHI



Easyfundraising is a wonderful free and easy way of supporting the charity. It costs nothing to you and CHI gets funded from your purchases online. It really is *easy fundraising!*

Please sign up to it – it only takes a few minutes!

HERE'S THE LINK...

<https://www.easyfundraising.org.uk/causes/childhealthint/>

And please suggest this to a friend or family member. 😊 We think this is going to be a very useful source of funding for us. Many thanks if you can help fund us in this way.

And please also use...



Child Health International is registered with Amazon so just go to www.smile.amazon.co.uk (this particular link is important) and enter Child Health International in their search box and then Amazon donates 0.5% of the net purchase price (excluding VAT, returns and shipping fees) of eligible purchases to CHI.

Donations can also be made on the charity's website - <http://childhealthinternational.org/donate/>

Annual Report and Accounts

Our 2017 – 18 Annual Report and Accounts has been lodged with Companies House and the Charity Commission. Key points were:

- Activities continued to evolve in response to changing needs and opportunities
- A new focus on organisational, as opposed to narrowly medical, support
- A relatively quiet year after a burst of activity in 2016-17 but with real progress in active projects
- Expenditure was higher than income for the third year running; additional fundraising will be necessary soon.

If you would like a copy, please ask.

Data Protection

The only personal data which we keep is a list of names, addresses, telephone numbers and email ids necessary to contact supporters, donors and partners. We do not buy, sell or exchange personal data or use it for any other purpose than simple communication.

We hope that you would like to hear from us when we have something interesting to say and we promise that it will not happen more than three times a year, but if you would prefer we did not contact you again, just let us know at admin@childhealthinternational.org

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