



Child Health International

Helping children with Cystic Fibrosis live life

Summer 2020

Welcome to our summer 2020 newsletter!

First of all we would like to thank all our loyal supporters. This is a charity where a little goes a long way, but nonetheless that little is absolutely essential! Your support is hugely appreciated.

Of course Covid-19 has put the brakes on our travel plans for the time being, but we will most certainly continue our work as restrictions get lifted, and we are all looking forward to continuing to help improve the standards of health care for children and young adults with CF in the countries we are involved in. Standards of care in other countries can lag far behind the UK and this is an area of need that CHI is set up to help improve.

Greece



Clare Pearson CF Dietician Emma Major CF Physiotherapist Mary Carroll CF doctor from Southampton , Tes Hodson CF nurse specialist from Southampton, Filia Dimentea Director Athens Adult CF service outside Sismanoglio Hospital, Athens

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This is one of our most successful projects which is currently ongoing and is led by Dr. Mary Carroll (Head of Adult CF Care in University Hospital Southampton and a Trustee of CHI). By working in close collaboration with doctors and other health workers in Sismanoglio General Hospital, Athens and the Adult CF centre in the North of Greece, Thessaloniki, Mary has overseen very real improvements in the provision of treatment of young adults with CF in Greece since the start of the project in 2015.

One of the reasons for the success of the project is the continual contact between the staffs in Greece and the UK. This has ensured a deep understanding of the challenges faced by the Athens service and made it possible for the Southampton team to provide appropriate advice informed by a sophisticated understanding of the challenges faced in Greece.

The Planned exchange Greece/UK visits that were due to go ahead this year were postponed in March due to the Covid-19 epidemic but will resume as soon as it is feasible.

Background

Following a request for help from CHI by the Hellenic CF Association (HCFA) in Athens, CHI arranged a fact-finding visit to Athens in April 2014. The visit was organised by Rod Halls and included Dr Mary Carroll and other specialists from University Hospital Southampton (UHS).

They found the service in Athens under considerable strain at that time with an almost overwhelmed single CF Consultant, no outpatient services, no home visits, very limited physiotherapy and no dietitians. CF was massively under diagnosed which probably meant the known number of cases was less than half of all sufferers.

The project was launched in November 2015 with a full multi-disciplinary team from UHS visiting Athens and this has led to frequent exchange visits between Greece and Southampton over the following four and a half years involving doctors, nurses, physiotherapists, hospital manager and others, and Dr Mary Carroll holding a regular clinic in Athens 3 times a year.

Project aims and methods

The objectives of the project are to demonstrate exactly how UHS deploys a multidisciplinary team in providing CF healthcare, to offer training and to make recommendations about the organisation of CF care in Greece – all of this taking into account local constraints and limitations on resources.

It's a supportive relationship in which a rapport is established between the Southampton and Greek teams, and the team from Southampton also learn things in the process. Mary comments that the whole of her department is fully signed up to this project.

Sometimes CHI will fund accommodation but frequently a doctor, nurse or other health worker visiting Southampton from Greece will stay as a guest in one of the homes of a Social worker or nurse here. Same goes for visits to Greece by doctors and nurses from Southampton.

The project is providing assistance on all fronts in terms of know-how and best practice and of course people with different medical skills have a programme individually tailored to their particular requirements when visiting this country. Always the overall picture is looked at and how the teams in Greece work together bearing in mind their local challenges.

Dr Katerina Manika's visit

An example of a three month visit that took place last year would be the visit of Dr Katerina Manika (Assistant Professor of Pneumonology) who was due to take over the running of the CF Centre in Thessaloniki after the retirement of the then senior director. She came to Southampton in preparation for her new role.



Dr Katerina Manika

Dr Manika spent time with each member of the CF Multi-Disciplinary Team - specialist nurses, physiotherapists, dieticians, pharmacists, social workers, CF psychologist, specialist Microbiologist and palliative care team. The Southampton team provided her with protocols in each of these areas and particularly pharmacy protocols for IV antibiotics. In addition, she attended adolescent transfer clinics run in the paediatric department, the purpose of which is to smoothly transfer adolescents over to the adult CF service. Dr Manika spent time with our service manager who discussed organization and delivery of CF services, which included management of a Multi-Disciplinary Team, infrastructure and logistics around maintaining an efficient, well-resourced service.

In a thank-you letter Dr. Katerina Manika wrote:

“My training on CF care in Adult Cystic Fibrosis Service in Southampton England has been a multidimensional experience which I hope will change my every-day work in Greece. I would like to thank all the members of the multidisciplinary team for their time and for sharing their knowledge and experience with me. I am also grateful to Child Health International and in particular Mr. Jim Hopwood, chairman of the board of trustees of CHI for making this training possible. I would especially like to thank Dr Mary Carroll for coordinating this complex training, for introducing me to different and wider way of thinking on CF care, and for always making me feel welcome.”

Community Nursing Service

There have been several trips by CF nurses in both directions, funded by CHI, to establish a Community Nursing Service so that a home Intravenous antibiotic service can be set up in Athens; an important development that avoids the need for people to come into hospital when they can be effectively treated at home.

We have achieved so much but there is still so much we need to do to support our colleagues in Greece. There is a need to assist in setting up a smooth Transition service from the paediatric to the Adult service. Greece is establishing lung transplantation and we will be able to offer our experience in this area.

Now is a very exciting time in CF research with the availability of new CF drugs. We have already supported the Athens team in their selection and in the doing of these drug trials. We feel we have developed a good working relationship with our Greek colleagues and would like to continue to contribute to the benefit of Greek CF patients.

Russia

History

Following the founder, Roy Ridgway's visit to Moscow in 1992, a Moscow – Southampton CF project was launched and the medical team was led by our current President, Dr Chris Rolles, and ran from 1993-96. Before 1993, there was only public funding for Russian CF care if a patient was an in-hospital patient, i.e. there was no effort to keep patients out of hospital or well, at school and leading a relatively normal life. One result of the 3 year project was a doubling of life expectancy for Russian children almost no Russian reached adulthood in the mid 1990s.

So there has been a longstanding friendly relationship with Russian CF. Amazingly, the head of Russian CF in 1993, Professor Nikolai Kapranov, is still active. There has been occasional collaboration over the years, mostly between the Royal Brompton Hospital (RBH) and CF personnel in Moscow.

Current

On a private visit to Moscow in August 2019, Tony Wolstenholme (former Chairman, CHI) renewed contact with Professor Elena Kondratyeva, Head of the Russian CF Service, visited her hospital at Mytishchi, NE Moscow and also had a meeting with the NGO Ostrova ("Islands") in St Petersburg. Elena sought a revival of collaboration with RBH, chiefly for young doctors and her priority was CF physiotherapy masterclasses – there is an acute lack of this vital 'therapy' skill in the Russian Federation. Neither physiotherapists, nor dieticians have the kind of status – or salary – that their UK counterparts enjoy.



Specialist nurse, Judi Maddison (far right front) from Southampton with the Russian CF nursing team in a conference room at the Yaroslavl hospital

Future collaboration was on the agenda too when Dr Mary Carroll, Specialist nurse Judi Maddison from UHS and Chairman Jim Hopwood attended a CF conference at Yaroslavl on the Volga NE of Moscow in November, Mary presented a paper on Transition from paediatric CF care to Adult care and Judi on the role of a specialist nurse (in UK, this is the main link between the CF family and the CF Centre). Their inputs were well received. There is only one Adult CF Centre in the Russian Federation.

Dr Gary Connett of UHS, Dr Chris Rolles and Tony Wolstenholme were invited to join the celebrations at the end of June this year, marking the 30th anniversary of the Russian CF service – all expenses paid and no cost to

CHI. Covid 19 caused us to decline the invitation – and in the end, the celebration was postponed. The Covid 19 situation is particularly acute in Moscow – like London and New York - with 694,230 cases as of 7th July and 10,494 deaths – probably many more in reality.

Owing to Covid 19, a two-week internship at Royal Brompton Hospital for a young CF Doctor from Moscow, planned for September has had to be re-scheduled for March 2021. She will join an international on-site one week course and then shadow a CF paediatric respiratory consultant during the second week. Provision of two two-day CF physiotherapy masterclasses in Moscow and Kazan, Tatarstan is in the planning stage.

Lastly, much of the funding of our medical assistance to Russia comes from a Russian-based charity, Ostrova, in St Petersburg founded by an oligarch with a soul! We try to make the most of this generosity.

Bulgaria

Child Health International has been working closely with Bulgaria since 2013.



There are 4 CF centres in Bulgaria (Varna, Sofia, Plevan and Plovdiv) which are spread throughout the country. At the time of our initial visit to Sofia there was very little interaction between the centres and, as a result, no significant information sharing. At each centre, there are highly motivated professionals but there is an absence of a recognisable multidisciplinary team (specialist CF nurses, dietitians etc.) with many of the roles fulfilled by single individuals.

Child Health International has helped establish a twinning association between Southampton Children's Hospital and University Hospital St. Marina, Varna. This has enabled health professionals to undertake multiple reciprocal visits to both organisations providing an excellent opportunity for collaborative learning and sharing of ideas. By close observation of working patterns and systems, it has been possible to identify strengths and weaknesses which have directed changes to clinical processes and plans for future development. As an example, following a visit by professionals from Varna to Southampton Children's Hospital in 2017, a number of valuable techniques for microbiological surveillance, and hence early antibiotic intervention, were observed by the team from Varna and subsequently implemented at University Hospital St. Marina.

Following a number of visits to Bulgaria Dr Julian Legg, a paediatric CF specialist and medical officer for CHI, concluded that one of the most useful improvements to the management of CF in the country would be the development of a robust, detailed register of CF patients. 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.



*Members of the Varna Cystic Fibrosis Team visiting Southampton Children's Hospital with Dr Julian Legg, Director of Wessex CF Services, in 2017.
From left: Assoc Prof Georgieva, Dr Legg, Dr Galabova, Dr Natalia and Dr Pancheva*

Latvia

Good news from Latvia! Our involvement in this country goes back many years and in 2017 there was a successful visit by a group of doctors from Latvia to the Birmingham Children's Hospital. The objective was to help build a programme to introduce neonatal screening for all newborns in Latvia.

Dr Maya Desai (consultant respiratory paediatrician) and other medical staff at Birmingham Children's Hospital very kindly gave their time to host the team to observe screening techniques and discuss what was needed to introduce them. At the end of their visit the Latvian team were all set to go in setting up the screening programme but unfortunately, although their government had agreed to fund it, the funding was indefinitely postponed due to a political situation.

However we are pleased to report that neonatal screening for CF has now commenced in Latvia and is working effectively. Inevitably it will save lives and is an important step in bringing Latvia closer to European standards of CF care.

India

India is a very big place both geographically and in terms of population, and in 2005 we arranged a visit to the UK by doctors and health workers from all over the subcontinent. This was the culmination of a series of exchange visits between Southampton and India over several years.

The project led to a number of further initiatives resulting in the increased recognition and development of services for individuals with CF across the Indian subcontinent and included the development of CF teams to provide models of care using locally available resources.

In an exciting new development to help further improve CF services in India, we funded a scoping visit to India in October 2019 by Professor Garry Connett (Consultant Respiratory Paediatrician) from University Hospital Southampton (UHS) to help adapt the UK CF database to suit the whole of India. The visit entailed travelling within India to a number of sites to meet with local care providers and to discuss how best the initiative can be implemented.



Dr Connett's primary contact in India is Professor Sushil Kabra at the All India Institute of Medical Science (AIIMS) in New Delhi who was a key figure in CHI's earlier project.

Dr Connett has already obtained funding to cover the cost of adapting the UK CF database for India now that the groundwork is completed.

Dr Kabra at his outpatient clinic for children with CF in New Delhi



A recent endorsement of the work of CHI by Dr Mark Rosenthal Consultant in paediatric respiratory medicine at the Royal Brompton Hospital, London.

“Since 1994, I together with a team from the Royal Brompton Hospital London, have provided CF training and clinical expertise with the logistical, financial and language support of CHI to Lviv, Odessa and Kiev Ukraine, Vilnius Lithuania and Minsk in Belarus. Some projects were more successful than others and crucially relied on the face to face rapport one tries to develop. The support CHI gives is fundamental in facilitating these efforts and without it, they would have all foundered or become deplorably ‘in hoc’ to pharmaceutical companies. I would be very much saddened if CHI withdrew such efforts as despite all the advances from the internet, access to online journals, webinars etc, the level of medical education and the value placed on allied health professionals by so many countries remains woefully poor.”

CHI Funding

As we approach the end of our financial year in July it looks as though our income for the year will be about £3600; £2350 from regular small donations by our 30 long standing loyal supporters boosted by £1050 Gift Aid on those donations and £250 from fund raising activities. In a normal year we would expect the fundraising element to be stronger; Covid-19 has curtailed such activities.

Expenditure has been about £9000 on project work and just £250 on administration (mostly meeting room hire). We really can claim that virtually all the money we raise is spent on our charitable activities.

In reality, the benefit delivered is worth much more than this. All our UK medical personnel are volunteers; their time alone would cost many thousand pounds otherwise. Travel costs are often split with the host organisation; all internal accommodation and travel in Russia was covered by the conference organisers, we only paid for visas, air fares and UK travel.

The planned meeting in Bulgaria will be funded by the local branch of the Abbott pharmaceutical company on a similar basis. This has been an unusual year with fundraising activities restricted by Covid-19 and relatively expensive fact finding visits to Russia and India to explore the possibilities for future work.

But even so, it is clear that we need to increase our fundraising urgently. We can only operate within our means and we provide excellent value for money, but more funding is greatly needed to maintain and increase the scope of our work.

Bike Ride to Paris

Fundraising initiatives by individuals are hugely welcomed by us all at CHI and in June last year, Michael Ridgway (age 71) and his cousins Alex Clarke (also aged 71) and Erika Leece (a little over 60) cycled to Paris for CHI. They raised a total of £2,790.90 from sponsorship of their trip.

Löic Lopez (Michael’s son-in-law) was their support driver who took the tents and provisions ahead of them to subsequent camp sites. He would set up the tents and then wait for them to catch up. When they eventually did, he would have a delicious vegetarian meal underway for them all.



Michael, Erika and Alex on a bridge over a tributary of the Seine

The bike ride started outside the main entrance of University Hospital Southampton from where Alex and Michael cycled along the South Coast to Newhaven. There they met up with Erika and the three of them plus Lőic took the ferry across to Dieppe. They then cycled along the Avenue Verte (an assigned cycle route) to Paris.

Michael writes:

“It was one of those never-to-be-forgotten experiences and a real adventure. About a third of the trip in France was along a disused railway line that had been surfaced for cycling. This gave us our easiest cycling. The remaining two thirds was much more varied!



Arrival in Paris

Mainly it was on minor roads but some major roads and many hills!

We had very changeable weather with sunny periods interspersed with some terrible downpours. It got very windy too and one night the winds and driving rain were massive as we huddled in our lightweight tents! It would get very cold at night too, much colder than normal for that time of year.

The countryside was lovely and whenever we stopped (during sunny periods) we noticed the birds were singing all around. Many of the beautiful small towns and villages seemed strikingly deserted, like it was lockdown already.

On a sunny day we stopped at Monet’s house and explored the spectacular gardens with more flowers than you could almost imagine – and there was the bridge over the lily pond.

For the final stretch, Lőic went on ahead by car to collect a bike from his mother’s place then cycled with us into Paris through the elegant outer suburbs of the city, the parks and along the Seine.

The weather completely settled on that day and stayed glorious for the couple of days we spent exploring beautiful Paris, and it was a delight to stay with Lőic’s mother Madeleine who was a wonderful host. We returned in very good spirits by car with our bikes mounted on the back!”

If you think you could raise money for CHI by doing something similar, we would love to hear from you. Or maybe you can think of a friend or family member who could be interested. These challenges can be great fun and can give you a treasured memory of a great experience. And they are so thoroughly worthwhile in how they raise money for such a good cause. You may like to do a cycle ride to Paris too! Please contact us with your fundraising idea!

We encourage any ideas you may have but we do have a place in next year’s London Marathon and are looking for a well connected runner! Could that be you?

Email: chairman@childhealthinternational.org or write to The Chairman, Child Health International, 18 Woodlands Close, Dibden Purlieu, Southampton, SO45 4JG

Please Donate if you can

Individual donations are the lifeblood of this charity and we are extremely grateful to all those who already support us. So if you already support us – thank you so much!

If you have not yet donated anything and would like to do so now, or if you already donate on a regular basis and would like to contribute more, here are some ways you can do this.

You can donate quickly and easily with a credit or debit card by clicking this red button...



Or go to www.virginmoneygiving.com and type Child Health International into the search box. This will get you to the appropriate page.

Set up a Standing Order

You can support us with a Standing Order or Single Payment by Bank Transfer.

If you are a UK tax payer please use the gift aid tax form that means we can claim an extra 25% from the tax man. Click on [gift aid form](#)

Please make your Standing Order or Single Payment payable to...

Child Health International Co-op Bank Sort code 08-90-34 Acc 70306459

Kindly draw our attention to your donation by sending an email to chairman@childhealthinternational.org or send a written note to The Chairman, Child Health International, 18 Woodlands Close, Dibden Purlieu, Southampton, SO45 4JG



← Click button

Please remember to use [easyfundraising](#) every time you shop online. Over 4,000 shops and sites will donate to us, including all the big names like eBay, John Lewis & Partners, Argos, ASOS, Expedia, M&S, Just Eat, Uswitch and many more! This means you can raise FREE donations for us no matter what you're buying. It really is an excellent way of supporting CHI!

If you haven't signed up to support us in this way yet, it's easy and completely FREE. These donations really help us, so it would be great if you could take a moment to get started!

Thank you!

Donate with a Cheque

We are always very grateful for the occasional cheque! Please write to us or complete this form and put it in the post with your donation.

I would like to contribute to the work of CHI and I enclose a donation of...

£10.....£25.....£50.....£100.....£300.....£500.....£1000

Other.....

Name.....

Address.....

.....Post Code.....

Email.....Phone.....

Cheques payable to: Child Health International

Please post to The Chairman, Child Health International, 18 Woodlands Close, Dibden Purlieu, Southampton, SO45 4JG

If you are a UK tax payer please use the gift aid tax form that means we can claim an extra 25% from the tax man. Click on [gift aid form](#)

Include us in your Will?

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.

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 from time to time when we have something interesting to say, but if you would prefer we did not contact you again, just let us know at admin@childhealthinternational.org

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