

Child Health International

Summer 2006



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Cystic Fibrosis (CF) in India

Over the last few months, one of Child Health International's main projects has been to forge links between the Southampton General Hospital CF Unit and the Indian Cystic Fibrosis Working Group, which is setting up a CF network to cover the 1.1 billion people across India. Originally considered a condition of Caucasians alone, there are now recognised CF sufferers across all races and nationalities, as Dr. Chris Rolles, a long-term CHI collaborator writes:



Sarvari, daughter of a rickshaw driver in Delhi, is diagnosed with Cystic Fibrosis using Dr. Sushil Kabra's sweat testing machine.

Cystic Fibrosis (CF) was first described in 1938/39 in Europeans. At the time, it was assumed that it didn't occur in other racial groups. Occasionally this condition was recognised as being mild, but in around 70% of cases, if untreated, it was known to lead to death within the first months or years of life.

With optimal treatment in the West today, life expectancy is well into adult life and there are cases who are currently aged 50 or more and there are healthy young people with CF who have gone to university, or women with the condition who have had children.

Early in the 1970's, the first cases of CF were described in Indians and Pakistanis living in the UK and USA. It was widely taught that it didn't occur in Asians and even today some medical schools teach that CF is only a Caucasian problem.

Over the last ten years, a few cases have been described in pure Chinese and black Africans. So the condition may be universal although much less common in some racial groups than in others. In the West, CF is well defined with a lot of research into how the condition actually affects the body and into more sophisticated and often very expensive treatments. (*contd. overleaf*)

CHI projects

India

Link between Southampton General Hospital and Indian CF Network

Lithuania

Linking Vilnius University Clinic and Frimley Park Hospital

Contact us

Child Health International
44, Richard Moss House
St. Peter Street
Winchester
Hants SO23 8BX
Tel: 01962 849342

Email:
info@childhealthinternational.org

Website:
www.childhealthinternational.org

Trustees:
Michael Ridgway
Dorothea Ridgway
Marcus Haw
Alexandra Clarke
Stephen Todd
Andrew Edmondson
Rick Foulsham

For example, for the 8,000 or so people with CF in the UK, the average cost of treatment is around £20,000 per year with some specialist individual treatments costing £10,000-£15,000 per year just on their own.

About eight years ago, one or two very astute doctors in India recognised some cases of CF and began to develop a service for these children. They had read about CHI's work in Russia in collaboration with the CF team in Moscow which showed that tremendous gains could be made with this condition at a fraction of the cost of Western care.

Child Health International has responded with exchange professional visits to India and now as a start, there are six centres with clinics that can diagnose and treat CF while developing low cost approaches – "appropriate technology" at its best!

In December 2005, Child Health International arranged for five Indian specialist doctors to come to the UK for intensive training and exchange of views with the Southampton General Hospital CF team. From this came a very exciting and ambitious plan to undertake research in India to get accurate data on the incidence of CF (possibly more than 10,000 cases per year) and to devise local methods of diagnosis and treatment.

Already the senior doctor in Delhi, Dr. Sushil Kabra,



Dorothea Ridgway, Dr. Chris Rolles and members of the Indian CF Group at Southampton General Hospital

has invented a diagnostic sweat testing machine (used to diagnose cases of CF) that can be made for less than £10; this should be compared with the Western hi-tech version which costs approximately £3,000, yet the Indian version is not significantly less accurate.

The development of this collaboration will not only help literally tens of thousands of Indian children to live but will also help to enhance understanding of CF and its management worldwide.

To the Baltic!

*CHI has been starting up a new project to help children with CF in Lithuania. While a member of the EU since 2004, Lithuania still lags some way behind the UK in terms of treatment, so we are hopeful that we can repeat the successes that we achieved in Russia and Ukraine. **Brandon Taylor**, Project Manager, has sent us the following report:*

A successful visit took place to the children's department of Vilnius University Clinic, at the centre of Lithuania's healthcare system and having a well-deserved reputation as the specialist unit for Cystic Fibrosis in this small Baltic country. Most CF patients in Lithuania do not survive beyond the age of 18 and are treated with a variety of approaches based on antibiotics, dietary supplements and some physiotherapeutic regimes. Leader of the visit was Dr Ronald Knight from the specialist CF unit at Frimley Park Hospital National Health Trust, with his registrar Dr James Hull, who has a keen interest and a growing expertise in the field.

Dr. Knight gave a Power Point lecture in the ancient lecture theatre of the hospital, explaining his preferred techniques, which was well attended by doctors from several other disciplines as well as by CF specialists.

Following the lecture, Dr Knight held a clinic for some six children between the ages of six and fifteen, and gave advice on treatment which was appreciatively received.



Pictured here (from left to right) are Dr Hull, Professor Valiulis, Dr Knight, Dr Indratyte and Professor Dumcius, the chief CF physician for children in Lithuania.

On the following day, Dr Knight and Dr Hull visited the main adult branch of the Vilnius Lithuania Hospital and had a fruitful exchange of views with Dr Rolandas Zablockis and Dr Elena Bernotiene, the main physicians for the relatively small, but growing, number of adult CF patients in the region. The British group was shown the equipment and the facilities of both branches of the hospital.

It is hoped that Professor Dumcius and Dr Zablockis will visit England to see facilities in Southampton and Frimley Park later in 2006 and build on the very positive relationships already established during the March visit.

Change is underway at CHI!

New Office

The sharper-eyed of you will notice that our address has changed – this reflects the current make-up of the charity's volunteer force and the way we operate. Individual projects are now managed by members on a more decentralised basis, with the wonder of the Internet and e-mail making it easy to keep everyone up-to-date with matters, and to ensure that expertise and advice can be readily shared between projects. As a result though, we have reduced our physical office space, as there is not currently a need for a single, central location from which we can work on a day-to-day basis. This allows us to make sure that even more of our supporters' funds go to where they're needed – helping sick children. Rest assured though, that even if the office has now become "virtual," our work is still as real as ever, and Winchester is still our spiritual home!

New Fundraiser



While we couldn't do what we do without the help of you, our long-term and everyday supporters, we have recognised that there are some projects where the financial need is such that we need to approach a different audience.

With this in mind, we have managed to secure the services of John Launder as a volunteer dedicated to

fundraising. John will be focussing primarily on raising funds towards the £40,000 cost of the first stage of the Indian project from businesses and groups across the South of England (see front cover).

New Trustee

We are delighted to welcome Rick Foulsham aboard as a Trustee. Rick, who lives near Micheldever, worked for many years in the Foreign Office, and is currently Chief Executive of Hope and Homes for Children, a charity helping orphaned, abandoned or vulnerable children in Eastern Europe and Africa. We know that his skills and experience will be invaluable to CHI going forward.

CHI NEEDS YOU!



Could you help out CHI? We are looking for active new Trustees and volunteers, to help run projects, raise funds or just make things work! If you'd like to help make a difference in any way, please contact us.

About CHI

We thought it might be useful to summarise here briefly what we do, and why we think our work is deserving of your support.

CHI was set up in the early 1990s by Roy and Dorothea Ridgway in memory of their son Tony, who died from CF at the age of 29, having lived far longer than anyone had expected. Roy had previously worked with International Physicians for the Prevention of Nuclear War, and when the Iron Curtain came down, decided to use his contacts to help improve treatment for CF patients in the former Soviet Union. Several projects were undertaken in Moscow, Odessa and Lviv which were highly successful in changing the focus of treatment from the supplier (the doctor) to the receiver (the patient), and in including treatments outside the hospital, such as physiotherapy and nutrition, into managing the condition. From here, CHI branched out into other illnesses, such as cardiac disease.

Roy sadly died in late 2000, but his work has continued in the same vein, moving from Russia to other countries where we think we can help.

Our intention is not to spend money on providing drugs, as it is the provision of a whole treatment regime that is critical in greatly improving the lives and increasing the prognosis of these children. We concentrate on fostering a sustainable environment where diseases are diagnosed early, and treatment is carried out both by medical professionals, and where possible, by the child's family. We achieve this by arranging the transfer of know-how from doctors, nurses, physiotherapists, family support groups and other parties with whom we have links in the UK to their equivalents in the countries where we work. By encouraging treatment to expand beyond the walls of the hospital into the home, we can improve the lot of the sick child with a minimum of financial investment. And because all of us are volunteers, your support goes direct to helping those who need it the most – the children!

On yer bike!

*Some people, it seems, will go to the ends of the Earth to help CHI. Trustees **Michael Ridgway** and **Alex Clarke** with friend and CHI supporter, **Guanyu Chen** did this as best they could while staying in the UK with a sponsored cycle ride from Land's End to John O' Groats! Michael sent us this report:*

To be honest, my cousin Alex and I were really not entirely sure we could make it - we are both 58 and - er - could we really cycle a thousand miles?! I had intended to get into training with this but somehow it was difficult to find the time and the furthest I had managed was on one occasion from Winchester to Stockbridge and back which was about 22 miles. I had never actually owned a bike since I was twelve and so I was not really very bike proficient but I ventured into a Winchester cycle shop and bought a brand new one with 27 gears especially for the trip.

I thought it was going to be just Alex and me, but then student/artist Guanyu Chen who was exhibiting her paintings at CHI's art exhibition at the Guildhall in Winchester volunteered to join us.



So it was the three of us - Alex, me and Guanyu aged 26. We head off from a sunny but very windy Land's End on October 1st 2005. You may be able to picture us cheerily setting off: Alex and me - the two getting-on-a-bit ones on our brand new bikes and kitted out with all the gear and the young Chinese one with a more rickety borrowed bike wearing a big warm coat. Possibly a slightly odd sight, the three of us, but we had confirmation that we were believable as genuine cyclists after less than ten minutes into the ride when a motorist who I think had been held up by us momentarily came alongside, wound down the window and yelled at us "Cycle fanatics!" And there I was thinking I had "car driver" written all over me.

We started rather late in the year of course and there was concern about what the weather would be like but I went to some length to reassure everyone that it can be shown statistically that it doesn't rain in this country nearly as much as people think and that you can normally expect it to remain fairly dry. "Rain is a bit of a myth" I explained.

My prediction stood up quite well for the first two weeks but I was proved so terribly wrong later on, especially after our first stop in the Lake District. An

idyllic location with mountains all around, mist cascading down the mountains, beautiful autumn colours - but then the rain set in with a vengeance! A nearby river began to burst its banks and the field that we had pitched our tent in began to flood - it was a race against time to get the tent down and out of the field. We all thought - "we can't cycle in this weather", and so we just managed a couple of miles to the next hostel where we stayed the night

But the rain was still as severe the following day and it began to dawn on us that we couldn't wait for it to stop so we carried on cycling regardless. This was when I realised that all these wonderful waterproofs that we had spent so much money investing in were not very effective when it got really wet. Somehow the wet gets in if it is raining hard enough! If it is not the rain it is the fact that the rain causes the outfit not to breathe and so with all that pedalling you are drenched through with your own sweat!

We would take time off to savour our journey and look around but at the same time we did do a lot of serious pedalling. We pedalled hard and long most days. Prior to this ride I had simply never cycled 30 miles - nowhere near - but 30 to 40 sometimes 50 miles in a day was quite normal for us and it was a real eye opener to me to realise how far you can get on a bike! We seemed to get stronger as we went along and often we were cycling at a high speed!

On the road we would stop off somewhere for lunch and we would always take small provisions, bags of nuts, crisps, chocolate to give us energy and of course plenty of water. We would often stop somewhere nice in a field by the road and have a picnic (when it wasn't raining) and sometimes we would turn in at a pub and have a ploughman's lunch (or whatever). Supper was usually in the tent. Alex and Guanyu were the "cooks" and we eat superbly I have to say.

For me the part of Scotland beyond Inverness had a special appeal - the clarity and purity of the air and the light was somehow magical.

The trip was an experience of a lifetime, a real adventure and good fun - there were a lot of laughs along the way I can tell you! It has certainly given me a perspective on this island that I couldn't have got in any other way, a real feeling of the extent of the country - a sense of conquest almost over it and we were very happy to have raised from all our generous sponsors almost £4,000 for CHI.

Do you have an idea for fundraising for CHI? If so, we'd love to hear from you! Please call Dorothea Ridgway on 01962 849342 or email info@childhealthinternational.org