



Child Health International

In many countries right now, children with cystic fibrosis are dying unnecessarily due to inadequate treatment.

Together, we can change this.

Welcome to Our Summer 2023 Newsletter

First of all, we would like to thank you for your continued support of Child Health International. Child Health International is run entirely by volunteers and we rely on the contributions of our loyal supporters to continue our important work, and to help improve the lives of children and young adults living with cystic fibrosis. Your support is vital, so from all our team, thank you!

Adapting to changing times

Due to the ongoing impacts of COVID 19 and the differing rates of vaccine roll out across our partner countries, travel and face to face meetings have remained virtually impossible until very recently. However, with the need for our services greater than ever, Child Health International quickly adapted, adopting new ways of working and utilising new technologies to engage our partners remotely. Rather than hinder our work, this new way of working has opened many new possibilities, allowing us to develop new relationships while also strengthening existing ones.

Looking to the future, we're excited to be able to get our medical volunteers back together, engaging with patients and upskilling local professionals, but the skills we've learnt from the last few years will not be lost. By utilising these remote capabilities alongside our traditional face to face approach, we're confident that Child Health International will reach more people than ever, improving the lives of ever more children and young adults living with cystic fibrosis.

Read on to find out what we've been doing since our last newsletter, and to learn about our exciting plans, developing invaluable and accessible online content for overseas practitioners and getting back to face-to-face and peer-to-peer learning in Greece and Bulgaria (see below).

In Memoriam

It is with very much regret and sadness that I have to report the passing of Dr Chris Rolles, the charity's President, on 4th January 2023. Chris was not only the President of the charity but instrumental in establishing its *modus operandi*.

Chris' involvement with the charity started with a visit to the Republican Children's Hospital in Moscow in 1993 at the behest of Roy Ridgway, the charity's Founder, where he found that the funding of CF care only applied to in-patients, most of whom were quite seriously ill, and even that care was rudimentary with little key basic information recorded; there were no out-patient clinics. As a result, Chris agreed to a joint project between the Moscow CF service, led by Professor Nikolai Kapranov, and his CF department at Southampton General Hospital.



This project lasted three years from 1993 to 1996 and, by the end, life expectancy of Muscovite children had doubled through the establishment of an out-patient clinic and introduction of a basic multi-disciplinary approach to care involving not only CF consultants but physiotherapists, specialist nurses and dieticians. However, Chris was not only the medical lead but negotiated substantial funding from the pharmaceutical company, Solvay (now merged into Abbott), which not only funded the project but also supplied Creon and other vital medicines. It was this project that provided the framework and objectives for similar 'twinning' projects in Eastern Europe and other countries over the last 27 years.

On a personal level, he was perhaps the natural children's cystic fibrosis consultant; something of a "cuddly teddy bear" and blessed with a great sense of humour. But Chris went further, supporting and encouraging his staff and in many cases, influencing their future careers as CF specialists in their particular field. Chris was appointed President some years ago, a small token of esteem and gratitude for all that he brought to Child Health International and in his career in medicine.

He will be dearly missed.

Recent Activities

New additions to the charity



Last year, we were fortunate to welcome Prof Gary James Connett as a Patron of Child Health International. Gary is a Professor of Paediatric Respiratory Medicine at University of Southampton and a regional director for paediatric CF services across Wessex and provides comprehensive secondary and tertiary specialist services for respiratory problems in children and young people. Gary also served as paediatric representative for the UK CF Medical Association and as a member of the Research Scientific Oversight Board for the CF Trust. Gary is obviously held in very high esteem in the international CF community and has already provided valuable input, including educating the team on how CFTR modulators work and consequently, the benefit they bring to CF patients.

Over the last two years, there have been a number of changes to the Board of Trustees and we now have an excellent team of the most medically qualified Trustees than at any point in the charity's history. The Trustees are further supported by experienced Project Managers and the charity now works with assistance from CF specialist organisations both in the UK and abroad. We can therefore export, with

confidence, best practice in the treatment of CF to those countries requiring help through both visits and internships. It also means that we have access to the most up to date treatments and techniques and can quickly adapt to changes that will inevitably take place over time in the treatment and management of CF. Details of our new members can be found at the end of this Newsletter.

The War in Ukraine

It is with deep regret that Child Health International has had to suspend collaboration with our colleagues in the Russian Federation in response to the ongoing invasion of Ukraine. This is for the safety of all concerned.

Continuous symptom management is vital to the long-term health of those living with cystic fibrosis, making them particularly vulnerable to the current humanitarian crisis. We are also acutely aware of the strain that increased demand will place on existing services within neighbouring countries. In response to the invasion, we immediately reached out to the European Cystic Fibrosis Society ('ECFS') and CF Europe, offering our support to maximise the care available for those impacted or displaced by the ongoing violence. This offer of assistance is on-going and will remain as long as it is needed.

As mentioned in the Introduction, this unfortunate situation has also made us adapt, adopting new ways of working and utilising new technologies to engage our partners remotely as explained below.

Presenting patient cases to UK multidisciplinary teams

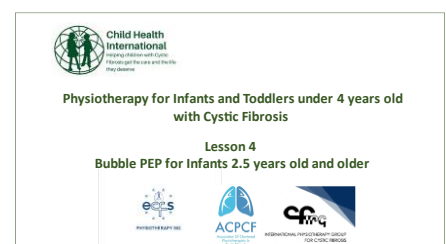
CHI is helping CF teams in other countries by providing support in the management of patients through video consultations between local and UK based CF multidisciplinary teams.

Despite the challenging travel restrictions imposed by the COVID-19 pandemic, CHI remains steadfast in its commitment to making a difference. By leveraging technology, CHI has been able to continue providing valuable support to CF teams globally.

The video consultations provide an avenue not only for local teams to benefit from UK-based specialists' expertise but also enable CHI to gather valuable insights on CF management in different countries. This information is used to develop bespoke resources and training programs tailored to the specific needs of each country.

On-line Master Classes in Physiotherapy

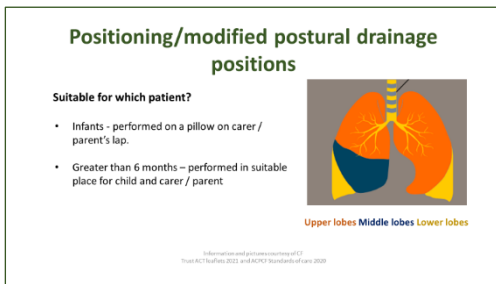
Recognising in January 2022 that travel and resources could be problematic for some time and given the pressures on medical staff due to the pandemic, a project was launched in that month to produce an on-line library of videos and presentations covering the various disciplines, starting with physiotherapy. This section of the library is being produced in collaboration with:



- ❖ Association of Chartered Physiotherapist in Cystic Fibrosis, a UK and Ireland based organisation;

- ❖ International Physiotherapy Group in Cystic Fibrosis, an international organisation with representatives from over 40 countries;
- ❖ European Cystic Fibrosis Society's Physiotherapy Special Interest Group;
- ❖ A CF Trust funded PhD programme; and
- ❖ CF Physio.com, an Australian physiotherapy group.

We have further reached out to associations covering CF specialist nursing and nutrition to start similar videos and presentations and this year will be seeking to expand the library to cover CF psychology, palliative care and possibly pharmacology.



To make these videos and presentations available worldwide, we will be seeking to have the videos interpreted and presentations translated into French, Spanish, Portuguese and Russian in order to reach and educate as many CF medical personnel, patients and parents/ carers in the latest treatments and techniques.

Russian Forum of Medical and Social Organisations

In November 2021, we provided four speakers for the third Russian Forum of medical and social organisations entitled “Let’s Unite our efforts in the battle against cystic fibrosis” dedicated to the memory of Professor Nikolai Kapranov in Yaroslavl. This was an on-line conference with our speakers covering:

- ❖ Palliative Care and Lung transplantation over 30 years at the Adult CF Centre in Southampton UK;
- ❖ Home hospitalisation unit - allocation of responsibilities (patient, relatives, doctors);
- ❖ Growing up with CF: adapting physiotherapy through adolescence;
- ❖ Sports or physiotherapy? An alternative or a necessary supplement?; and
- ❖ Collaboration both Internationally and at home. An essential approach to obtain the very best outcome for CF patients.

The mundane but important stuff!

Organising visits and internships is all very well but being a charity also means that we are subject to a plethora of laws and regulations. Time was therefore taken during the pandemic to ensure full compliance with the 2020 Charity Governance Code, the Charities Act 2011 that was subsequently amended by the Charities Act 2022 in Autumn last year and the Data Protection Act 2018. Further work was also carried out on improving communications and the website.

CFTR Modulators

In 2015, the first Cystic fibrosis transmembrane conductance regulator (CFTR) modulator was licensed for use in the UK. This new class of drugs acts by improving the production, processing or function of the defective CFTR protein from which the many symptoms of cystic fibrosis originate.

This is a huge breakthrough in the treatment of cystic fibrosis. For the first time, we are able to target the underlying cause of CF rather than simply manage the symptoms. Both Orkambi and Symkevi were made available on the NHS in 2019, Kaftrio in August 2020. We're now seeing a shift in UK CF centres, with a greater focus on out-patient treatment as fewer CF patients require in-patient care.

While these drugs offer a long-awaited ray of hope for many people living with cystic fibrosis, affordability remains a barrier to access in many countries. Unfortunately, this means that the services of Child Health International, educating overseas medical teams in basic CF treatment through both face to face visits and internships in UK CF Centres, will remain critical for many years to come.

What is planned for 2023

Bulgaria

In July, our Medical Advisor, Dr. Julian Legg, will be attending a three-day conference in Varna, accompanied by a physiotherapist and a dietitian. The conference will be attended by representatives from all four CF centres in the country, and it represents an excellent opportunity for us to extend our support.

Dr. Legg's participation will be further bolstered by Lutz Naehrlich, Head of the ECFS European Registry Database. Dr Naehrlich is actively working towards getting all European Centres to submit regular data to the European database to enhance patient advocacy, collaboration and sharing of best practice. Dr Legg and the team will be supported by Adrian Gamble, Project Manager, who has supported teams on previous Bulgarian projects.

Dr. Legg's presentation will focus on CFTR modulators and their remarkable impact on patients in the UK. This presentation is of significant importance, as it is anticipated that the centers will soon have access to these modulators. By sharing our expertise and knowledge, we can help improve the quality of life for CF patients in Bulgaria and make a positive difference in the ongoing fight against this debilitating condition.

Greece

Dr Mary Carroll, Director of CF services at Southampton, is the Trustee responsible for Greece. Mary has been involved with the CF centres in Athens and Thessaloniki for a number of years and has seen the centres develop and then impacted by lack of resources, more recently by Covid 19, when staff were

reassigned to other wards. Mary is in the process of arranging a conference in Greece between Southampton and Greek Healthcare Providers to determine their needs post the introduction of the highly effective CFTR modulators.

Estonia, Latvia, Lithuania and Moldova

Due to the pandemic and more recently the war in Ukraine, active collaboration with these countries was suspended. Whilst the Ukrainian situation continues to have an impact, the situation has at least stabilised to the extent that we feel comfortable approaching these countries again to determine whether we can help, especially given the introduction of the CFTR modulators in some countries. In the case of Estonia, the team will be led by Dr Julian Forton in Cardiff who was involved in the project with Estonia in the past. This project will be supported by Tony Wolstenholme and Juulia Zumer, Project Managers, who are both Russian speakers. Juulia also speaks Estonian!

Spotlighting our Amazing Fundraisers



In September 2022, Laurie Ridgway completed the 'Big Half 2022' in 2 hours, 15 minutes and 55 seconds, raising £551 in sponsorship to help us develop online resources – the Master Classes - to improve cystic fibrosis care abroad.

Also, a huge thank you to Taylor Carlile, who, in October 2021, ran the virtual London Marathon and a week later, the 50km John Muir Way Ultra, in support of Child Health International.



Running is all very well but for our Chairman's daughter, Harriet, she prefers to stand ... on the wing of a plane whilst it is doing acrobatics!



Harriet had a double lung transplant nineteen years ago and consequently it was necessary that she sought clearance from her various consultants who all agreed that from a medical point of view there would be no problem, but she clearly needs her head examined!

A date has yet to be set but she will be raising money not only for Child Health International but her local CF Centre at Frimley Park Hospital. So please keep an eye on our website for details of how to support her.

Volunteers needed to run The 2023 Big Half London Marathon on 3rd September 2023

We have three places allocated for the Big Half Marathon in September and all that we need now are RUNNERS!

So, if you are a runner and would like to volunteer to run for us and raise money in the process, please email us at events@childhealthinternational.org



Meet the Team

Since the last Newsletter in the Summer of 2020, there have been some significant changes and additions to the Board.



Kerry Rait joined Child Health International as Trustee and Director of Media and Communications in November 2020. When not editing and improving Child Health International's ever evolving website, Kerry works as a Principal Scientific Advisor for the Scottish Government, following a career in biogeochemical research and environmental advocacy. Kerry is also a Befriender for East Lothian charity Held in Our Hearts and a freelance editor for the CF Trust. As a proud mum of three and having lost her middle son to complications linked to cystic fibrosis, Kerry is a dedicated and engaged member of the Child Health International team.

In January 2021 Judith Maddison joined the board. "Judi" is a Paediatric CF Nurse Specialist at Southampton Children's Hospital. She has worked in CF for over 30 years and was part of the original team who worked with CHI and the Moscow service. Throughout her career, Judi has been involved in several of the CHI partnerships, helping to develop CF services in many countries. In the last 30 years, Judi has seen many changes to CF care and the expansion of the CF nurses role. Judi is passionate about equality of care, both nationally and internationally and believes that every service has much to learn from each other. Partnerships across nations offer the opportunity for exchanges of skills and learning, which can benefit all CF patients – wherever they call home.





And in February 2021 Tracey Daniels, a CF Physiotherapist, joined the Board. Tracey is a physiotherapist and research fellow at the York and Hull adult CF Centre. Tracey has worked with adults and children with CF for around the last 20 years in several UK CF centres. Within Child Health International, Tracey provides a link to the allied health professions such as physiotherapists in order to best support our partnership working model.

In June 2021, Jim Hopwood resigned as Chairman of the Board after 10 years in the Chair and David Wilford took over as Chairman. Before retiring, David was a regulatory risk consultant with over 45 years' experience in banking, advising

international banks on the implementation of and compliance with PRA, FCA and European regulatory requirements. As for his connection with CF, it goes back nearly four decades when his daughter was born with CF and five years later, he became Chairman of the Berkshire branch of the CF Trust. Nineteen years ago, his daughter, Harriet, had a double lung transplant and is now married with an eight year old son, so miracles do happen. As for interests, David qualified as a PADI specialist dive instructor while working in Saudi Arabia. It was a simple choice: either join the diving fraternity and enjoy diving in the Red Sea or running in the desert in 40c – 50c of heat with the Hash Harriers ... so no contest there!



In September last year, Juulia Zumer joined us as a Project Manager. Juulia has a degree in Economics and Management Sciences and is experienced in a vast variety of project management skills. She is also a PRINCE2 Practitioner and holds PSMI certifications. More importantly, Juulia is fluent in English and Russian and speaks some Estonian, which, given our focus on Eastern European countries, makes her a very valuable addition to the Team. Her work-life motto is "Planning is not optional", which is probably a good thing given that one of her hobbies is sky diving!



We were also joined in September by James Eustace as Project Manager. James is a commercial and contracts manager for the School of Healthcare Enterprise and Innovation, which sits within the Faculty of Medicine at the University of Southampton, and previously worked for the National Institute for Health Care Research. His work is in supporting medical research and innovation projects that he finds very rewarding. James is married with a six year old son, William, and when not working, enjoys getting out and about with the family and visiting lots of new places, as well as sailing around the south coast and local kayaking.

This year, the charity welcomed back Adrian Gamble, a former Trustee who acted as Project Manager for our relationship with Bulgaria between 2014 and 2018, and who will again organise a visit planned for this summer. Following an early career as an investment banker, Adrian spent 20 years as a Senior Civil Servant in the Foreign Office, with postings to Brussels, Rome and Vienna, and 3 years supporting the Prime Minister's Office in No.10. He has spent the last 10 years or so as a Director in Deloitte's Strategy Consulting practice and more recently as a Director of Fair Trader.



Finally, we were going to appoint Prof Natasha Kashirskaya as Special Advisor on Russia in January last year, but this appointment has had to be suspended for her protection until the situation in Ukraine is resolved.

Brief details of our other Trustees, Dr Julian Legg, Dr Mary Carroll, Michael Ridgway, Paddy O'Grady and Project Manager, Tony Wolstenholme, can be found on our website at www.childhealthinternational.org

Donate Now to Help Children with Cystic Fibrosis

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!

We cannot emphasise enough that by focusing on the low cost basics of cystic fibrosis management, small changes can make a huge difference. Help us make that change by donating as follows:

❖ **Donate as you shop**

There are over 4,000 shops and sites on board ready to make a donation including eBay, Argos, John Lewis, ASOS, Booking.com, M&S, Expedia, Just Eat, Uswitch and many more. And it won't cost you a penny extra to help us raise funds. All you need to do is:



1. Visit easyfundraising and sign up for free.
2. Every time you shop online, go to easyfundraising first to find the site you want and start shopping.
3. After you've checked out, the retailer will make a donation to Child Health International at no extra cost to you whatsoever!

It really is an excellent way of supporting Child Health International. So, 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 through Charities Aid Foundation**

If you have a Charities Aid Foundation account, click [here](#) to go to the CAF website, select the 'Donate' option and follow the instructions.

❖ Donate with a Cheque or via Bank Transfer

Please make cheques payable to **Child Health International** and post to Child Health International, 11 Holland Close, Chandlers Ford, Eastleigh, Hants SO53 3NA.

If you prefer to donate via direct bank transfer, please email us at admin@childhealthinternational.org and we will gladly provide you with full bank details.

Whichever way you decide to donate, please do not forget that if you are a UK tax payer we can claim an extra 25% from the tax man if you complete a [Gift Aid Tax Form](#) and either scan and send it to the above email address or by post to Child Health International, 11 Holland Close, Chandlers Ford, Eastleigh, Hants SO53 3NA.

It would also be appreciated if you would draw our attention to your donation by sending an email to chairman@childhealthinternational.org or send a written note to our Chairman with the form to the above address.

Charity Gift Aid Declaration – single donation

Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:

I want to Gift Aid my donation of £_____ to:

Name of Charity _____

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

My Details

Title _____ First name or initial(s) _____

Surname _____

Full Home address _____

Postcode _____ Date _____

Please notify the charity if you:

- want to cancel this declaration
- change your name or home address
- no longer pay sufficient tax on your income and/or capital gains

If you pay Income Tax at the Higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

❖ Set up a Standing Order

You can also support us by setting up a Standing Order in which case, please email us at admin@childhealthinternational.org for bank details. And again, if you are a UK taxpayer, please use this multiple donation [Gift Aid form](#) so we can claim an extra 25% from the tax man every time that you donate. Please either scan and send the form to the above email address or by post to Child Health International, 11 Holland Close, Chandlers Ford, Eastleigh, Hants SO53 3NA.

❖ 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 Child Health International in your Will, or you have any questions about this, do contact us at admin@childhealthinternational.org. 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 that 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 or wish to change how you receive these emails, please just let us know at admin@childhealthinternational.org. If you would like more regular updates on our work, please visit our website at www.childhealthinternational.org or on Facebook at www.facebook.com/ChildHealthInternational/

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