**CHI – Successful events over 30 years of collaboration with Russia.**

**Introduction.** The founders of the charity, initially named the International Integrated Health Association, were Roy and Dorothea Ridgway. Roy was a peace campaigner and, as a member of a group campaigning against nuclear weapons, was invited to Moscow to receive a peace prize. He and Dorothea had lost a son, Tony, at the age of 29 from cystic fibrosis. More or less on a whim, they decided to visit the Republican Children’s Hospital and see how patients with CF were treated ….. so began CHI’s main business – the raising of standards of CF healthcare in Russia, Ukraine and several countries of Central and Eastern Europe.

Successful events are listed below. Events that have current significance are asterisked. The date of the success is indicated in brackets.

* Roy and Dorothea Ridgway visit the Republican Children’s Hospital to see how CF patients are treated – and realise the Russian children deserve better. (1992)
* Roy and Dorothea found a charity, the International Integrated Health Association, and register it with the Charity Commission. Trustees are appointed. (1992)
* It is likely that Roy and Dorothea knew Dr Chris Rolles, Consultant Respiratory CF physician at Southampton General Hospital as he probably treated their son, Tony. They shared their thoughts of Russian Children with CF with Dr Rolles, who promptly agreed to go to Moscow and see the situation with his own eyes. (1993).
* It is appropriate to understand the context of the times, which you will appreciate were very favourable. The Soviet Union had come to an end at the close of 1991. The Cold War was over. The West and the EU had robust policies to support the Russian Federation and there was little shortage of funding either from the EU (TACIS) or the UK Government (The Know How Fund). (1993).
* Dr Rolles decided that there was much he could do to improve the treatment regime in Moscow. A 3 year collaborative project was set up between the Moscow CF service and Southampton, 1993-96. Substantial funding was given by Solvay Pharmaceuticals, now merged into Abbott. (1993).
* In 1994, a child born with CF in the UK had a life expectancy of 25; in Moscow, 11. The UK emphasised sustaining children’s good health through out-patient monitoring, whereas funding for care in Russia depended on CF hospitalisations, disincentivising prevention. Doctors were dominant, and CF families totally ineffectual in advocating for better standards of care. Care in the UK averaged $15k/year (including e.g. lung transplants); this project set a target of $1k/year for Moscow, prioritising early diagnosis (through neonatal screening) and prevention (no passive smoking, regular out-patient clinics, meticulous health records, tailored dietary advice and specialised physiotherapy) by which it is possible to achieve 80-90% ‘wellbeing’ for <10% of UK costs.\*
* At that time, there was no Zoom, Skype and it was early days for emails. The collaboration relied on regular face to face contact and so travel between Moscow and Southampton. “Comradeship” (to use a Soviet term!) grew warmly between the two teams – Dr Chris Rolles, Judi Maddison (Nurse specialist) and the Moscow team led by Professors Nikolai Kapranov and Natasha Kashirskaya, which flourished for over 25 years. Friendship flourished in part because it became the norm to stay in each others’ houses/ flats. Professor Kapranov sadly died on 8th March 2021 from Covid 19 infection. (1993-96).
* At the end of the project, life expectancy of a CF patient in Moscow had doubled to 22 years and the wisdom of treating a sick child with a multidisciplinary team was accepted. (1996).

From 1997 onwards there was mainly a period of steady consolidation of CF healthcare in the Russian Federation and CHI’s attention was drawn to Ukraine and Odessa in particular.

* In early 2013, CHI and Dr Rolles, who was by then retired as a doctor but was CHI’s President, received an invitation to join a 20th anniversary celebration of the start of the Southampton- Moscow project. Dr Rolles declined the invitation after visa application problems and his wife, Dr Toni Rolles, had a health issue. After some negotiation, it was agreed that CHI’s patron, Mrs Rosie Barnes, former CEO of the UK’s CF Trust would travel to Russia and, after more discussion, she would present a paper, based on her experience at the CF Trust, recommending that the Russian Federation might follow suit with a Unitary Authority, representing Doctors, associated medical professionals, Scientists, geneticists, patients and their families instead of their somewhat separate bodies – a mainly CF Doctors’ organisation with little obvious influence on CF research and minimal CF parent involvement and separate, independent-minded patients’ support organisations …. Making for a rather fragmented interface with the Russian Ministry of Health. Rosie Barnes made the same presentation at a conference organised by Ostrova in St Petersburg and in Moscow at the National CF Congress. We learnt that a good way to get the message across is to have the powerpoint presentation in Russian, while speaking English in a slow, measured manner …… or speaking with pauses if an interpreter service is available. A method whereby the powerpoint presentation is in English but the aural message is the interpreter’s translation into Russian is likely merely to create confusion.\* (2013).
* Interestingly, following a review of the Russian CF organisation by a Dutch professor (report dated 02/07/2014), Professor Tiddens recommended parents support organisations coming together into one body, quite close to a version of the UK’s CF Trust. \*
* Rosie Barnes and I deduced that there are 4 components to the **Russian CF organisation structure.**

(i). The "OOO" All Russian Association for those with CF, whose President was Professor Nikolai Kapranov. It is based in Moscow at the Republican Children's Clinical Hospital and organised the 11th National CF Congress. It has 3 supervising working groups but it is chiefly a medical forum with strong research and genetics elements. Its priority is medical care; parents and parents support groups are little involved.

(II). Ostrova. A charitable fund, supported by a Russian philanthropist and based in St Petersburg. It supports CF care in St Petersburg, partly funds "Help for those with CF" ((iii) below), funds several kinesitherapy centres across Russia and runs projects, which enhance the lives of young CF persons. It is the only serious funding NGO in Russia.

(iii). Parental Support Groups (PSGs) , such as "Help for those with CF", run by Irina Myasnikova. It depends partly on funding from Ostrova. It seems to focus on the rights of CF patients and their families as well as striving to ensure affected families receive their disability allowances.

* (iv). Funding charities. Quite small and fragmented, aiming to raise money for medication or treatment of individual patients.\*
* Regarding **Specialist medical training.** We noted that, whilst standards of child CF care in Moscow and St Petersburg have reached good standards, care of CF adults is in a formative phase and, outside these centres, some skills are lacking. These range from diagnostic skills in more remote areas at the primary care level (compensated to a degree by the advent of neonatal screening), a marked lack of specialist physiotherapists to limited numbers of specialist dieticians and psychologists. At the adult level, some additional training is desirable for doctors, specialising in endocrinology, gynaecology and psychology. \* (2013).
* **CF care funding.** In Britain, the Government, through the NHS, funds the CF service - medical staff and medicines - but the CF Trust raises much money, given voluntarily by donors, both to help families and support research. This latter supplementary funding function in Russia is undertaken by Ostrova - but is more reliant on a single philanthropist's generosity. Different countries .......... different cultures, but it is concluded that an insight into the role of the CF Trust in Britain would be useful for some of those managing Ostrova and PSGs. \* (2013)
* On conclusion of attendance at these two conferences, a number of recommendations was made but few were subsequently pursued – partly because it was agreed that the new Head of Russian CF, Professor Elena Kondratyeva, would come to London and spend a week with the Adult CF department at RBH from 16-23 November and this in itself was going to lead to a review of future collaboration. One recommendation at this time concerned the **CHI Medical Adviser.**  Although it is probable that more Russians will come to UK as a part of this project, it is recommended that CHI's medical adviser, Dr Julian Legg, should visit Russia to meet key personnel and see the environment in which they work. This might take 7-10 days and would include visits to the Republican Children's Clinical Hospital, Moscow, St Olga's Hospital, St Petersburg and two regional CF Centres - perhaps in Archangel and Orenburg. \* (2013)
* This is an example of a recommendation never pursued …… **PSGs/ Fundraising.**  It is recommended that a small group of those involved in the support of CF families in Russia be invited to come to UK for 3-4 days to study the role of the UK's CF Trust and learn more about charitable giving/ fundraising. At least one day would be spent at the CF Trust and some time with a local PSG. One day would include a hospital CF clinic. Based on our experience this year in Russia, candidates for such a visit would be Nikolai Moskovstsev, Mark Bensman, Julia Shamanovskaya, Elena Tyurina , Irina Myasnikova and Olga Alyekina.\* (2013)
* Professor Elena Kondratyeva (Head of Russian CF service desig) came to RBH for one week, principally in the adult CF department with Dr Di Bilton. (TW was programme coordinator and interpreter for 3 of the 5 working days). This was a very intensive week – and it was agreed before Elena went home that she would come back for a further week in the paediatric CF department in July 2014. Elena’s choice of UK and RBH to deepen her knowledge of CF was significant – and a reflection of RBH’s standing in the CF world. \* (2013/14).

(TW resigned from CHI wef mid 2014 and from Sep 2014 – March 2016 underwent 7 operations on his right knee, unable to drive during this period or walk without crutches).

* At a July 2014 meeting held at RBH, Professor Kondratyeva and Ostrova proposed sending a small group of senior Doctors and health service managers/ Ministry of Health officials to UK to be briefed on how the UK CF service, in the context of the NHS, is organised. (Note: We had done this for the Ukraine CF team from Lviv in 2002 … senior CF doctors plus a local authority health service manager plus a Deputy Head from the Ministry of Health in Kiev, plus a Dzvin NGO representative. This may have been useful to the Ukrainian side with regard to funding the service and availability of key medicines). At a follow-up meeting in December, the Russian side withdrew this proposal. Comment: Possibly a “step too far” ….. any possible changes in Russia would not be practicable. Alternatively, it was judged not to be a priority issue, for example, versus the great need to generate practising CF kinesitherapists and dieticians. \* (2014).
* The Russian side enquired about short-term internships of 1-2 weeks’ duration. Little progress followed and it is an issue not resolved – and post Covid – even in 2021. See below – re **online courses** at RBH.
* RBH informed the meeting that they were considering presenting a “MDT CF case of the month” via videoconferencing to help in the education of other (presumably UK based) CF MDTs. This would cover detailed treatment advice as well as show how the MDT worked together. Could the ‘monthly case’ be relayed to Russia? No decisions were taken but it is an offer that could be made to our Russian CF colleagues, which would probably need the Russian side to provide a competent simultaneous interpreter – and probably to other CHI partners. \* (2014).
* Professor Elena Kondratyeva returned to RBH for one week in late November 2014 with Dr Siobhan Carr and the CF paediatric department. During her time at RBH, a follow-up meeting to the July 2014 meeting took place. Rather significantly – and probably because Natasha Kashirskaya lives in the Netherlands – the Russian CF service in Moscow had been reviewed by Professor Tiddens of the Erasmus University Medical Centre in Rotterdam. He made a series of recommendations and pledged the support of EUMC in implementing them. His recommendations included:
* Uniform cross-infection prevention.
* Better collaboration between the CF team and other hospital specialists.
* Rationalise / improve physiotherapy provision.
* More nutritional advice.
* Encouraging the various parents’ associations to merge. (comment: to form a body more like the UK’s CF Trust)
* Developing a research capability with a view to joining the ECFS Clinical Trials Network and accessing research funding.
* Developing an Electronic Patient Dossier.

Notice too that he identified dietary advice and CF kinesitherapy as elements of CF requiring improvement – but does this involve major changes in the training and status of Russian dieticians and physiotherapists or the extension of doctors’ training to include these additional skills? \* (2014) As of 2021, we are unaware of the progress of the Tiddens recommendations.

* **Online CF course.** RBH designed an online distant learning CF course and also a one week on site course. The online course was designed for all CF medical professionals – Drs, physios, dieticians, nurse specialists and pharmacists etc Anyone who passed the course became eligible for an onsite internship of about 2 weeks’ duration. At the 2014 July RBH/ CHI meeting it was proposed that the online course should be translated into Russian ….. so that young Russian CF doctors, anywhere in the vast Russian Federation could take the course. It is not clear who funded the translation – possibly either RBH or Ostrova. Ostrova took on the role of promoting the course by publicity and additionally Ostrova paid the course fee, set at £350, to all, who passed the course. Though the online course was available, maybe from 2015 onwards, very few Russians joined the course – and even fewer subsequently came to RBH. When I resumed the role of project manager, Russia in Autumn 2019, I began enquiries about the online course and the low number of Russian participants. Dr Su Madge is the Course leader and Liz Holder is the course administrator. Covid 19 began in March 2020 …. And the onsite courses have not taken place since then. I asked several times to see the online course in English and Russian but my requests were declined. Then RBH advised me that the online course was being updated. To translate the revised course, Su Madge had received a quote of £50,000. I thought about approaching a Russian oligarch, whom I know. On reflection however there are at least two ways of looking at the online course, as follows

1. The online course is only available in English. Only Russians with a good level of competence in English and medical terminology can do the course. If they pass and then come to RBH for up to 2 weeks’ CF experience, they almost certainly have good enough English to gain serious benefit from an internship at RBH.
2. RBH has produced a fully up to date online course in English with good lecturers. A similar online course could probably be produced by the Russian CF service, albeit it might be weak on CF physiotherapy and CF dietary advice. One option might be to licence the RBH new version of the online course to Russia and let them undertake translation into Russian as well as giving them the right to modify guidance to suit Russian circumstances. It is possible Ostrova would fund the translation fees.

The Russian CF service could use both these options ….. with item I as a precursor for medics to come to RBH for CPD.

* + A “Russian School of Cystic Fibrosis” was organised mostly by Dr Siobhan Carr, RBH and Professor Elena Kondratyeva – in February 2016 in Moscow …. A kind of “Master Class”. It was the nearest the collaboration had been to a typical CHI MDT visit for many years. There was though no CF outpatients’ clinic. The team was Dr Siobhan Carr, paediatric CF respiratory consultant, Dr Su Madge, consultant nurse, adult CF care (now i/c Adult CF care RBH), Suzie Nolan, paediatric CF dietician and Fiona Cartwright, adult CF physiotherapist. Apart from local Moscow personnel, there were CF medical personnel from St Petersburg, Crimea, Stavropol, Izhevsk, Nizhny Novgorod, Rostoc on Don, Arkhangelsk and Smolensk. The Russian side chose the topics, which ranged from Transition from child to adult CF care, newborn screening, lung transplantation, CF nutrition, airway clearance techniques to fertility and pregnancy issues and CF related diabetes. Proceedings were filmed and used later in Tomsk at a training event for Siberian CF centres. (February 2016)
  + Collaboration was “dormant” between February 2016 and Autumn 2019, (Skripals poisoned in Salisbury March 2018) when two events triggered fresh initiatives.

1. A first Russian CF Forum, deliberately bringing together medical CF personnel and CF social welfare organisations at Yaroslavl, NE of Moscow on the Volga. CHI was represented by Dr Mary Carroll, Adult CF Consultant, Judi Maddison, paediatric CF Nurse Specialist, accompanied by Jim Hopwood, CHI Chairman. A good number of parents was present. Topics covered by the CHI team included transition from child to adult care, palliative care and clinical trials.
2. On a private visit to Russia, TW arranged to meet Elena Kondratyeva in Moscow and Olga Pylaeva and colleagues in the Ostrova offices, St Petersburg.

As a result of these two events, a rather confused array of requests was tabled by the Russian side. The following matters of substance formed an agenda for ongoing collaboration: -

1. To deal with a critical shortage of CF kinesitherapists, Russian Federation-wide, CHI to run some 2 day physiotherapy master classes in Moscow, St Petersburg, Kazan, Samara and to arrange these either in conjunction with a national Russian CF conference or with kinesitherapy courses organised by Ostrova in St Petersburg annually in April and September
2. A handful of individual requests for training at RBH, all of which will require each person to complete the RBH online course and to have a certain degree of competence in the English language.
3. Request for help on how to treat difficult cases – consultant to consultant via Skype, Zoom etc. This needs formalising …. Possibly with Su Madge/ Mary Carroll for adult CF patients and with Siobhan Carr for child CF patients.

The Covid 19 virus affected business with Russia from March 2020. Annual Russian CF conferences did not take place, including a special event to celebrate the 30th anniversary of the Russian CF service. In the background was the request for CF kinesitherapy masterclasses. In May, as Project Manager, Russia, I asked Elizabeth Shepherd, UHS and Tracey Collins, York Teaching Hospital if they would be the “master instructors” – they agreed. In early August, it was confirmed that the Yaroslavl conference, 12-13 November, would be virtual and preparations began accordingly.

* Concerning the Yaroslavl conference, we received additional requests for presentations, covering palliative care and the legal aspects of administering IV antibiotics at home and Care of a CF patient in the community (at home, at school). Judi Maddison, Nurse specialist, UHS took charge of these topics.
* Three general observations:-
* Whatever topic is to be covered by a UK speaker there is a need to understand what goes on in that particular context in Russia, thereby avoiding the possibility of “teaching grandmother to suck eggs”. For example, in kinesitherapy, we acquired a 2 ½ hour kinesitherapy webinar recording and a 45 minute powerpoint presentation by a St Petersburg kinesitherapist to parents before preparing our lecture.
* At this event, simultaneous interpreting was offered and was of a high quality. Even so, the speaker should not “gallop” but speak in a measured manner, pause – especially after making a key point – and pause again at the end of a slide to allow the interpreter to “catch up”/ even clarify a point made earlier in the slide.
* There was quite frequent reference to European standards or ECFS working groups.
* **GOSH infant physiotherapy guide.** As the lecture drafting got underway, Tracey flagged up the significance of the GOSH guide – for continuous assessment of a CF infant’s condition and we decided to use its main algorithm in the lecture. We also recommended the translation of the guide into Russian as an essential tool for Russian parents. GOSH authorised the translation under the usual terms. This was agreed on the Russian side and Ostrova agreed to fund the translation. The Russian version is to be posted on both the main Russian CF website and on the Ostrova website.\* (2020).

In conclusion this is a CHI Russian “timeline” and reflects successes over 30 years. It simplifies the task now to identify where clarification of Russian requirements is needed and will allow us then to develop an effective programme for the next 3-5 years.

26th May 2021 Tony Wolstenholme