

CHILD HEALTH INTERNATIONAL



Formerly "International Integrated Health Association"

Winter 2002/2003

CONCERT AT WOLVESEY

Mrs Scott-Joynt welcomed a full house, with standing room only for late arrivals, at a local charity Christmas concert held at Wolvesey, the Bishop of Winchester's residence.

Winchester Young Voices, conducted by Anne George, sang Christmas and Gospel songs followed by songs from Africa to a packed and delighted audience. This was followed by rendering of work by Berlioz, Palestrina and Bach on recorders by the Motley Company.

It was interesting to note that the age range of performers was 5 to 87!

In the interval everyone got together over wine and mince pies, old friends meeting and people interested in the work of Winchester based Child Health International as well as enjoying the lovely environment of the Bishop's residence.

At the end of the evening Marcus Haw Trustee of CHI and consultant paediatric cardiac surgeon spoke of the difference his work and that of Child Health International makes to children suffering from chronic illness.

He inspired a number of people to offer help in both monetary form and as volunteers for the charity.

The Young Voices and Recorders together sent everyone off with a beautiful rendering of The Lord Bless you and Keep you.



MISSION STATEMENT

CHI promotes a community-based system of healthcare, which puts the patient first and focuses on health of families in their physical, social and educational environments, with particular concern for those who are socially disadvantaged through chronic illness or disability. In carrying out its objectives, CHI seeks to bring together all those involved in the physical, mental and social wellbeing of men, women and children, including international agencies, national and local government departments, voluntary organisations, religious bodies, business and commerce.



The Mulberry tree in Wolvesey Garden

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CHI – AIMS AND TRACK RECORD

The International Integrated Health Association was founded in 1992 by Roy and Dorothea Ridgway, as a result of having a son with Cystic Fibrosis.

AIMS OF THE ORGANISATION

CHI believes health is a fundamental human right and regards the promotion of healthy lifestyles and the prevention of ill-health brought about through poverty, poor nutrition and environmental pollution as important social goals. The main objective of our work, which is community-based and multi-disciplinary, is the total care of the child beginning with the safeguarding of maternal health and early human development. Our main partners are (1) NGOs devoted to sex education and counselling among adolescents and young couples planning to have a child; (2) NGOs helping with the provision of medical care for children of refugees and street children; (3) NGOs helping with the training of community nurses and others involved in hospital outreach work and (4) support groups of families who are socially, psychologically and economically disadvantaged by the illness of a child.

History

We began by helping just a few children in Russia, doing what we could. This work soon grew though our main activities are:

- Working with Russian and Ukrainian cystic fibrosis (CF) charities and centres caring for patients in Moscow, Novosibirsk and Omsk in Russia; and Kiev, Odessa and Lviv in Ukraine
- Helping with the development of family support services in Russia and Ukraine
- Providing training for a children's heart surgery team in corrective heart surgery and post-operative care management at Moscow's Moniki Institute

The Russian Connection

A strong co-operative link with Russia was already established through key members' past connections. The work being done now owes its inspiration to Roy Ridgway, a medical journalist of international repute, who worked for the cause of peace for many years. Roy became a well known figure in Moscow, first as an executive member of the UK-USSR Medical Exchange Programme (now HealthProm) and European Press

Director of International Physicians for the Prevention of Nuclear War, who were awarded the 1985 Nobel Peace Prize, and now as founder of IIHA.

Since 1992, we have successfully undertaken a number of projects in Russia and Ukraine, including twinning hospitals in the East and West. These were centred initially on the treatment of cystic fibrosis, as this is an area in which IIHA had personal expertise: Roy himself had had a son with the condition. However, news of our successes has spread, and we are now working in the fields of cardiac disorders, cancer and reproductive healthcare, with investigations taking place into the viability of projects involving TB in the Caucasus and cancer in Moscow.

Partners

However, we do not believe in the short-termist view of pouring large sums of money away after drugs: our approach is to focus on forming partnerships with organisations in our target areas, and enable them both to raise their own funding for projects, and to put the resources they already have to more effective use.

TRACK RECORD

When the IIHA was inaugurated in 1992, CF treatment in Moscow was on a crisis management basis only. This meant that most CF children did not begin treatment until it was too late. The IIHA began in a small way, helping just a few children by suggesting improvements that could be made. Later, grants enabled help on a larger scale. What follows is a summary of achievements by IIHA from 1992 to the present.

Russia

- Bringing health-care professionals from the UK to the Republican Children's Hospital in Moscow to share knowledge about effective treatment; physiotherapy, monitoring, nutrition. The RCH is now regarded as a model of care throughout Russia and has set up clinics on the outskirts of the city.
- Helping parents of children with CF to set up a parent's group for mutual support and practical information.
- Arranging for doctors from Omsk and Novosibirsk to visit CF departments in England, allowing them to gain the

necessary skills to set up their own CF clinics back in their home country.

- Providing training for a children's heart surgery team in corrective heart surgery and post-operative care management at Moscow's Moniki Institute.
- Helping to set up "Living Water", a fund-raising and information providing organisation for parents of children with heart problems.
- Working with the Society for Children with Cardiovascular Diseases to improve family support services
- Working with the Moscow Blagocentre and The Magic Key (for Moscow children with cancer)

Ukraine

- Organising a project to help CF children in Odessa, following from an individual case. This included setting up a parent group and arranging for medical exchanges, allowing Ukrainian doctors to learn about levels of care in Britain.
- Extending our work in the Ukraine. After setting up a project in Odessa, the charity went on to contact hospitals in Lviv and Kiev, allowing CF children and their families all over the Ukraine to benefit from necessary drugs and effective treatment.
- Teaching parents of CF children effective counselling techniques

Lithuania

- Organising for a team of surgeons from Southampton General Hospital to perform operations on babies with heart disease in Vilnius.
- Helping parents of children with heart disease in Vilnius to set up a charity for mutual support, lobbying and fund-raising purposes.
- Bringing Lithuanian nurses to Southampton to study post-operative care for children and babies with heart disease.
- Translating medical journals and books from English to Ukrainian and Russian to enable Doctors in these countries to continue their studies into the condition.

LVIV, UKRAINE: MAKING AN IMPACT WHERE IT MATTERS!



"I have just spent one of the most rewarding weeks of my life." Not, perhaps, words you might expect to hear from a down-to-earth former Naval Commander and experienced traveller, but Lviv project manager Tony Wolstenholme has good reason to be pleased: Phase 1 of our current Cystic Fibrosis project in the Western Ukraine has already made an impact at Ukraine Government level, and with the company that supplies one of the most important drugs in the treatment of Cystic Fibrosis.

In December 2001 we heard that we had been awarded a grant for the project by the British Government's Department for International Development under its Health and Social Care Partnership. After months of preparatory work by CHI and by our Lviv partners, the Dzvin charitable Foundation, Tony took a small medical team from the Royal Brompton Hospital to Lviv at the end of April for an exhausting week of hands-on work. In addition to this, they were to play an important part in a major conference on the treatment of Cystic Fibrosis in the Ukraine.

The team was led by Dr. Mark Rosenthal, Consultant in Paediatric Respiratory Medicine, and included Specialist CF Nurse Jacky Francis, Physiotherapist Emma Dixon, and Nutritionist Lauren O'Shea. Michael Ridgway completed the team, tasked with recording the week's work on video as an aid to raising awareness about Cystic Fibrosis, and about the work of CHI and Dzvin.

The team had three aims. Firstly, to help doctors in the region to increase the number of cases that are diagnosed early. Early diagnosis is extremely important, as late diagnosis leads to irreparable lung damage, and is estimated to affect around 75% of all Ukrainian children with

Cystic Fibrosis. Secondly, to share information with parents, medical professionals and policy makers about the effective management and treatment of Cystic Fibrosis. Olga Hinka of Dzvin sees the lack of awareness about these as the main problem faced by families trying to deal with the disease.

The third aim was to help Dzvin and similar groups elsewhere in the Ukraine to develop a nation-wide network of parents' support groups, emphasising the important role that parents can play in the treatment of the disease, and the effectiveness of such groups in lobbying for – amongst other

things – better access to the prohibitively-priced drugs that are needed by CF sufferers.

The cost of drugs was a recurring theme in the clinics held by the team in three regional centres, Lviv, Ivano-Frankovsk, and Ternopol. Tony explains "We found plenty of well trained, caring doctors (on wretched pay) but the children need a regular supply of enzymes and antibiotics. These generally come free in the U.K., but in Ukraine almost all families have to pay for these drugs, and we frequently found that the cost exceeded family income by a factor of 3 to 5." This made it even more important to explain to parents the benefits of appropriate nutrition and physiotherapy.

Much detailed work was put into the organisation of the conference by Dzvin. They secured sponsorship for the event by Solvay Pharma, the supplier of the enzyme Creon, and went to considerable trouble to involve government health officials responsible for the treatment of Cystic Fibrosis in Ukraine. It was disappointing that the senior official had to pull out at the last minute, but CHI and Dzvin showed their combined negotiating strength by persuading an Ukrainian T.V. company to make a programme about Cystic Fibrosis, including many of the matters covered in the conference. This helped to boost awareness of the problems faced by Cystic Fibrosis sufferers, and kept the issue high on the public agenda.

All of the concerns about diagnosis, treatment and management of CF were discussed openly in the conference, with differences in approach getting a full airing. Emma Dixon's gentle approach to physiotherapy came as a surprise to some, whilst Lauren O'Shea's recommendation of a high fat diet was described as "Revolutionary". Dr. Rosenthal repeatedly stressed the benefits of teamwork in the treatment of Cystic Fibrosis. This "Team" involves doctors, nurses, physiotherapists, nutritionists and parents, with the specialist nurse taking on the management and co-ordination of the treatment. He pointed to Jacky Francis, who has this role at the Royal Brompton, suggesting that her role is more important than his! All agreed that the conference marked a real step forward in addressing Cystic Fibrosis treatment in Ukraine, and it was particularly touching for CHI that our hosts dedicated the conference to the memory of our founder, Roy Ridgway.



LVIV, UKRAINE: MAKING AN IMPACT WHERE IT MATTERS!

As all conference-goers know, much of the most valuable work at a conference takes place outside the formal sessions, and Lviv was no exception. A "robust" exchange of views between the CHI team and Solvay Pharma on the steps outside the conference centre led to further discussions inside, that subsequently resulted in the company offering to discuss the cost of Creon with the

Ukrainian government, and to sponsor the training of a physiotherapist from Lviv at the Royal Brompton Hospital. To their credit, Solvay have also agreed to cover the costs for the senior Ukrainian government official responsible for Cystic Fibrosis to attend the second phase of the project in the U.K. later this autumn.

Such was the impact of the visit to Lviv that the return visit to study our methods and structure in more depth has attracted considerable interest, and the rest of the Ukrainian delegation will be of a similarly high level. Amongst them, we look forward to greeting again Vera Novak, who will soon be the leader of the new national network of parent support groups in the Ukraine.

10 Year Anniversary opened by Mark Oaten MP

A summer's evening in Wolvesey, the Bishop's garden was the lovely setting for the celebration of the Charity's 10th anniversary and the launch of our new name - Child Health International.



Winchester MP, Mark Oaten opened the event with praise for the work of ICHA over the last ten years. "This charity does not have a high profile" he said "but has done incredible work with children in Russia, Lithuania and the Ukraine." He wanted to thank all the people involved who have organised the work and the visits and also the professionals who take their expertise to help set up groups of doctors and parents to help the children.

This is not one way traffic, the charity's work is to build up skills, pass on knowledge to others so that they can carry on themselves. He assured us of his support for the future of Child Health International.



Between the short talks, guests were enchanted by the delightful singing of Winchester Young Voices, who were led by their Musical Director Anne George. The 50 plus children sang a wide range of music, from pop songs to spirituals and African chants, and they concluded with a moving rendition of "May the Lord

Bless You and Keep You", which seemed entirely appropriate to the occasion.

The guests left at the end of the evening with plenty of music ringing in their ears, and with a lot of inspiration to help CHI move to the next exciting phase of its development.



BELGRADE CF CHILDREN WAIT ...



It was in response to a plea from the parents of one such patient that our co-operation with the YCFA began. Over the past eighteen months the lines have been buzzing with telephone calls, faxes and e-mails as the two charities swapped information, hopes, fears and plans, culminating in a fact-finding visit to Belgrade last March by a team from CHI, led by trustee and co-founder Dorothea Ridgway.

"Armed with the knowledge that we had

gleaned from our correspondence" explains Dorothea, "we needed to get to know our prospective partners on a more personal level. We also needed to make a hard nosed assessment of the benefits likely to be achieved by a project, and of our respective capacities to deliver them."

Dorothea was accompanied on the mission by Dr. Ron Knight and Specialist Nurse Jackie Hext, both from Frimley Park Hospital in Surrey, who were particularly interested in assessing the potential for successful collaboration with the medical professionals in Belgrade. As preliminary work like this is not eligible for grant aid, the funding for the mission had to be found by CHI itself, and we were lucky to be helped in this by two generous donors. To help keep the costs down, the CHI team was privileged to stay at the homes of families involved in the YCFA, and this helped tremendously in developing a good understanding between the two charities.

Following the visit, the reports of all team members suggested that a collaborative project was both desirable and feasible, and so another round of preparatory work began to establish clear parameters and a budget for the project.

In the short term, the project will provide training in early diagnosis of CF and sustainable methods of treatment. Alongside this, it will start work in



support of the longer-term goal to raise awareness about the disease amongst parents, health care professionals and the Yugoslav authorities. The ultimate goal of both CHI and the YCFA

is to develop a model training centre in Belgrade, comparable to the one we helped to establish in Moscow.

Responsibility for the preparation of the application itself fell to volunteer Caroline Hague, who comments "However early you start an application, it seems to be a law of nature that you end up eventually pulling everything together at the very last minute. In this case, Dorothea found herself delivering the completed application to the Charity Know How offices in person, with one day to go before the deadline!"



"If our application is successful, and we can make a real difference to the lives of these young people" reflects Dorothea, "it will all have been worth it!"

Dr. Ron Knight with Nemanja who has CF

UKRAINIAN HEALTHCARE DELEGATION VISIT ENGLAND



A team of Health Care Professionals from Ukraine, engaged in provision of medical care to children with Cystic Fibrosis visited UK between 26th October and 2nd November 2002.

The delegation included: Dr. Oleksandr Myndiuk, Chief Executive of the Lviv Specialised Children's Hospital, Dr. Yarema Vosnytsia, Head of the Paediatric Department of the named Hospital, Mrs. Nadiya Melnik, Deputy Head of the Lviv Regional State Administration, Prof. Oleg Gnateiko, Director of the Institute of Genetics and Hereditary Pathology, Dr. Ihor Hrytsiuk, Consultant Endocrinologist, Mrs. Svitlana Oryol, physiotherapist, and Mrs. Vera Novak, head of parents' support organisation from Kyiv.

SECOND PHASE

This visit was a second phase of a programme managed by Child Health International. The first phase took place in spring 2002 with a visit of a group of Cystic Fibrosis experts from the Royal Brompton Hospital, London. It had an aim to promote awareness of Cystic Fibrosis among the whole population, as well as improve diagnostic capabilities of doctors and provide them with advice on treatment.

ATTENDING CLINICS

During 6 days the Ukrainian team was briefed on different aspects of the UK healthcare system, attended Cystic Fibrosis Clinics at the Southampton General and Royal Brompton Hospitals, visited Paediatric Department of the Royal

Hampshire County Hospital in Winchester, the Cystic Fibrosis Trust in Bromley and the DNA Laboratory in NW London Hospital. Physiotherapist from Lviv Svitlana Oryol spent a week in the Royal Brompton Hospital studying physiotherapy techniques in children with CF. At the summary meeting at the end of the visit all the participants expressed their deep satisfaction of this visit and programme in general.

NEW CASES DIAGNOSED

Dr. Y. Vosnytsia: "After the visit of the UK team To Ukraine, with its positive repercussions in the media, we diagnosed new cases of Cystic Fibrosis. It is not unusual now that a mother comes to a doctor with a small child saying "Doctor, my child is coughing for so long. I am afraid it might be Cystic Fibrosis. Please check him (her)".

The return visit completely exceeded my expectations. I was deeply impressed by the team approach in work with patients in your hospitals, and that is worth implementing in our practice in Ukraine. I now know better what to do to improve our work in Ukraine and I am already building plans of how to do it".

Dr. O. Myndiuk: "This project was aimed to set-up a centre of excellence in CF in Western part of the Ukraine. I am proud to say this aim is achieved. Now it would be fair to share our knowledge inside Ukraine, between other hospitals and health care professionals. We are thinking of creating a mobile unit capable to travel to remote hospitals and providing patients with expert advice, as well as medical staff with logistic help and teaching. We have people able to do this, but we are still lacking a lot of equipment, therefore we are keen to continue our co-operation with CHI".

Mrs. Vera Novak: "We are about to create a nation-wide organisation in Ukraine, similar to CF Trust in the UK. This visit strengthened my determination to push harder on our government to give higher priority to cystic fibrosis treatment".

All the participants expressed their sincere gratitude to the project manager Mr. Tony Wolstenholme for wonderful organisation of the visit and all the trustees for the possibility to get acquainted not just with professional issues but with British culture and British lifestyle as well.



Rosie Barnes, Chief Executive CF Trust, receives a present from Vera Novak

THE WORLD'S SECOND BIGGEST CHILD KILLER

The majority of the world's children have no access to treatment for the planet's second biggest child killer – Congenital Heart Disease.

Whilst most countries have some form of health service, only a few can offer their children born with this killer timely access to the kind of treatment that saves thousands of young lives each year in the U.K.

Top children's heart surgeon and CHI trustee Marcus Haw identifies the southern Caribbean as an area that has a particular need for help in developing its paediatric cardiac service, and he believes that CHI could play an important part in delivering the sort of help that is needed.

"About sixty children will receive the necessary surgery this year in the southern Caribbean" says Marcus, "but around four hundred children need it. There is an urgent need to increase the volume and level of skills training in the area so that the paediatric cardiac service can deal effectively with the number of children who need its help."

Research is currently going on into the feasibility of a CHI supported project to bring urgently needed heart surgery to present day sufferers, whilst at the same time building up local capacity to meet the needs of affected children in the future.

Whilst there are different models for how this work can be done, it is likely that any future project would be based on a development of our successful work in Lithuania. It took just a few years and around £50,000 to establish a regional base for children's heart surgery and training in Vilnius, and the project continues on its own momentum, with increased local surgical capacity and continued support visits by surgeons from the U.K.

The preliminary stages of a project in the Caribbean would involve negotiations with governments, local hospitals and others to make sure that the particular local needs are clearly understood, and to build a solid foundation of trust between all those likely to be involved.

CHI would then have to mobilise a panel of surgeons who would travel with their teams to the region on a rolling basis to conduct surgery and support the training of local surgeons. CHI would also need to address such issues as the requirements for aftercare, and the roles of parents and voluntary organisations.

If the current research proves positive, and CHI responds to the call for help from the Caribbean, funding will be sought from the major institutions to support this work. The essential early work of building up local knowledge and trust between the partners, though, will - as in most of our projects - be outside the scope of many of the grants available. CHI will therefore be faced again with the need to fund the critically important preliminary work from its own resources. With the help and generosity of our supporters throughout the country, we will be ready to face this new challenge on behalf of the sick children of the southern Caribbean.

PROJECTS IN THE PIPELINE

We have some really exciting projects coming up. The first is actually an extension of the work we have been doing in Lithuania with some much-needed enhancements.

Lithuanian Children

We are now planning to bring a number of Lithuanian children suffering from congenital heart disease to the cardiac unit in Southampton General hospital complete with their own surgical team. The benefits are clear for the children – they will receive vital surgery not available in their home country – their surgical team will receive training and the skills to undertake similar operations when they return benefiting more children and finally the Southampton cardiac unit benefits by further enhancing their experience and International reputation.

The Southampton surgical consultants, surgeons and staff are giving up their own time to see this programme through - we now need to raise funds to cover all the ancillary costs of transport, accommodation and surgical supplies.

We hope that the majority of Post Operative care and accommodation will be provided by local families at no cost – volunteers please!

The second project is currently in its infancy but is broadly similar to the Lithuanian effort but will be based in Egypt. It is a terrible fact that hundreds of children die every year because congenital heart disease goes un-diagnosed and untreated – there is only ONE paediatric cardiologist in Egypt and he was trained by Marcus Haw our consultant cardiologist! Marcus will be speaking at a medical conference in Cairo in the New Year when he hopes to launch the CHI project.

Street Children at risk of Abuse, Odessa, Ukraine.

Dorothea Ridgway will be travelling to Odessa in the Ukraine as this newsletter goes to press, to receive an award for the humanitarian work of her late husband, Roy. While she is there she will, in response to a request for our help, meet with groups concerned about the abuse of Odessa's street children. She will be accompanied by Dr. John Stephen, an experienced collaborator with CHI under its former IHA title. Dr. Stephen also works on behalf of the Relief Fund for Romania, which runs a project for street children there, so he will investigate whether or not CHI can facilitate a link between the Romanian

project and the group in Odessa. In this way, Odessa could benefit from the knowledge and experience of the Relief Fund, so that it can get off to a good start in dealing with the problem.

Cystic Fibrosis Sufferers in Bucharest, Romania.

Discussions are currently under way to arrange an investigation into whether or not CHI can respond to a call for help from the parents of CF sufferers in Bucharest. It is likely that this would involve helping the parents to build up their own capacity and confidence to deal with the difficult circumstances in which they find themselves. A group of CHI supporters will shortly visit Bucharest at their own expense to do some preliminary investigation, and will report their findings to CHI on their return.

Whilst the tiny volunteer staff at CHI is more than fully occupied with a current live project, applications and research, calls continue to come in for our help in new places, and for children with different needs. The examples shown here are at the very earliest stages of research, but the needs of the children are as urgent as ever.

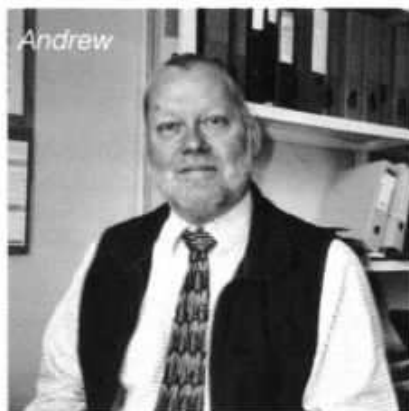
NEW OFFICE - NEW IMAGE

After the death of the charity's founder, Roy Ridgway at the age of 84 in November 2000, the group underwent a major rethink about its future. It was decided that the work should continue as Roy would have wished. Since then we have undergone many changes, the most obvious being in the change of name from International Integrated Health Association.

We have also moved offices, and are now based in the heart of Winchester. As we look out of the office window, we can almost reach out and touch King Alfred standing guard over his city.

To assist us with our work we have taken on some new faces as we continue to strive to make a difference.

We are very pleased to have ANDREW WHITE join as our new Chief Executive. Andrew brings with him 20 years of Sales and Marketing experience gained through a wide variety of directorships with both UK and International organisations. He is currently responsible for National Sales in the Financial Services Sector within Consignia (The Post Office to you and I!) where key areas of his interest are the development of targeted Direct Mail and Customer Relationship Management programmes. He has also worked alongside Charitable organisations in developing integrated advertising campaigns.



Andrew

He lives in the countryside near Winchester, is married with three children and his interests include motorcycling, clay pigeon shooting and reading.

"I'm really looking forward to working with CHI," says Andrew "and hope to contribute not only in the fund raising areas but also in the day to day running of the organisation. Most of all I'm just delighted to be involved in a charity that delivers such practical, no-nonsense help to child care teams in places where help is both desperately needed and also appreciated".



Donna was introduced to CHI through King Alfred's College where she is currently an employee in the library. She is very interested in the welfare of young people and saw this as a great opportunity to provide valuable support for those less fortunate than we are here in the UK. Her role involves helping out in the office, and dealing with donations. She feels very privileged to be involved in an organisation that promotes such positive change.



Donna

Gayle Chamberlain is a gap student who is currently working in order to fund travel to Southeast Asia. On her free days she helps out with the running of the CHI office. "When I first began work here in the beginning of October, I knew nothing about the work of CHI, but the more I learn about it the more I am encouraged to support it. I am inspired by the current CHI project that aids the sharing of information between Romanian and English Doctors, to better treat children suffering from Cystic Fibrosis.



Pauline

Pauline Stone first became aware of CHI (IIHA) when she applied for an accounts position to cover maternity leave. That was in 1998 and she is still here! "I have been involved in accounts all my life, it is something I enjoy doing because it gives me a great deal of satisfaction when all balances at the end of the month. Helping for a few hours each week gives my brain exercise, and the charity are able to do their good work."



Elina

Elina comes from Kazakstan and has worked with us for nearly a year. She brings her computer skills to the office and is invaluable when we need to contact our Russian and Ukrainian colleagues



Gayle