

CHERNOBYL CHILDREN'S PROJECT (UK)

ПОДДЕРЖКА ДЕТЯМ БЕЛАРУСИ

Kinder House, Fitzalan Street, Glossop, Derbyshire, SK13 7DL
+44 1457 863534 ccprojectuk@gmail.com www.chernobyl-children.org.uk

Visit to Belarus January 2019 *Brian Hardwick and Linda Walker*

Visit to Children in Trouble and Children's Cancer Hospital

Our first visit on Monday morning, with Valentina as interpreter, was to the office of Children in Trouble (CIT), where we were informed that Evgeny, Director for many years, will retire at the end of January.

Evgeny has been head of 'Children in Trouble for over 25 years and has done a wonderful job gathering support for the children and the hospital.



We had feared that when he retired the

organisation might fold, so were delighted to be introduced to Vera who will take over as the new Director. Vera is currently Executive Director of an organisation called "Touch to Life" which is apparently a big well-known NGO in Belarus. Touch to Life was established to help fund treatment for children with cancer, especially treatment abroad. They also provide practical essentials for parents staying at the hospital. They organised a radio appeal before Christmas and, as a result, were given 200 presents for distribution to the children in the hospital. Vera also organises a regular sports competition for children in remission from cancer and will bring this with her when she moves to CIT.

CIT have just been offered \$US 1M worth of medicines from US drug companies. They have also recently received funds to enable them to build their first website. We went with Vera and Nastia to meet Larissa the psychologist at the children's cancer hospital and were able to meet and photograph some of the children.



We met several children and their parents, some just arrived and waiting for a diagnosis and some who'd been there for a while and were continuing their treatment. One little girl called Margaret was 1 year old and had just been diagnosed with a brain tumour. Another beautiful little girl with big brown eyes has not yet had a diagnosis but has no immune system and has to have blood transfusions every 2 weeks.



Meeting with Rumak at Department of Social Protection

Next on the schedule for the day was a meeting with Alexander Rumak, Deputy Minister of Social Protection. We were informed that a new law guaranteeing the rights of disabled people was in the process of being drawn up and was currently out for consultation with many other interested parties including the other ministries. We were told that all at Social Protection are well aware of CCP's interest in deinstitutionalisation and that they have been continuing to discuss how to organise it. He continued that they understand the need to prepare young people and to be able to support them in the community. He cited the fact that Zhuravichi is no longer an institution for children as proof that they are trying to find families for children with disabilities and that they have been asking colleagues in the Ministry of Education why families don't want to foster children with profound disabilities.

Mr. Rumak then went on to inform us about a new "substitute family" initiative, aimed primarily at the well-being of disabled elderly people, that he said was being introduced in different parts of Belarus. This apparently involves identifying families whose own children have long grown up and left home but who still have the capability and desire to look after another person/s in their home. It is all done by private arrangement, in which the person requiring care and the "host" family sign a contract in which the finances are agreed. Often, but not always, this involves the person requiring care passing all of their state benefits to the host family and, in some cases, all of their personal assets too, in return for a place in their home. Social Protection merely provides a facilitation service, so it costs the state very little.

Regarding fostering, Rumak said that Social Protection would be delighted for more family homes to be set up along the lines of Klimovka but not by the state - that it would have to be done by NGO's with practical (not significant financial) support from the ministry. Support such as identifying suitable properties and paying for their renovation or refurbishment but not paying for salaries.

We talked to him about our new project with UNICEF. We hoped that he would be taking part in a major presentation of the work of the project which was due to take place in Gomel in the forthcoming month. But this event has since been delayed by UNICEF until the summer.

Meeting with Ina at British Embassy

The meeting with Ina at the British Embassy was primarily to discuss grants for Fostering Children with Disabilities. We had recently been granted just over £3,000 for a three month project, ending with a training programme which will be delivered to professionals and families by experts from Essex County Council during their visit in March.

Linda has already submitted a draft outline application for a follow-up project and explained to Ina that we want the grant to fund:

- a project manager for 30 hours per week.
- a family carer support officer
- a child support officer
- a special needs teacher for a few hours per week.
- a publicity campaign with posters and leaflets showing disabled children.

Ina sounded reasonably encouraging about the prospects of our winning a grant, though she reminded us that she would have to make a case for it to the Ambassador and others. She advised that we prepare a revised version of the application in which we change the balance a little – to put more emphasis on the "big picture" as well as how it will improve the lives of 25 specific children. She said that we would improve the prospects of success if we explain that the project will:

- help with the progress of getting people out of institutions.
- help with the changing of attitudes of the government to getting disabled children into foster families.
- encourage more families to consider fostering and adoption of disabled children.

Meeting at Minsk Main Railway Station with Elena Titova, Director of BELAPDI

The final meeting of our first day was held in the restaurant of the main railway station, just prior to our evening travel to Gomel.

For my benefit, Liena explained that BELAPDI is an organisation of parents of children with disabilities and has around 3000 members spread over 42 different locations in Belarus. She told me that it was set up to help keep disabled children in families by providing support. It now also focusses on their education (children with profound learning difficulties used to be considered uneducable and there were once no facilities for such people) and particularly on the needs of young adults. BELAPDI gets most of its funding by applying for grants to German, Swedish and American charities but the irregularity associated with this makes it very hand-to-mouth.

They've recently had funding for a project to produce a Good Practice Guide to Clear Language for use by experts, carers and institute staff. This promotes the use of simple, easy-to-understand language when communicating with people with learning disabilities. BELAPDI, along with 5 other NGOs has been instrumental in persuading the government to make specific reference to the rights of people with learning difficulties and mental disorders in the new law that Rumak had told us about earlier.

It was good to hear how closely Belapdi are working with the Ministry and that their expertise is being acknowledged and made use of.

Visit to Mayflower Centre

Our first visit on Tuesday was to the Mayflower Centre to meet Natasha and Tanya to discuss progress with the UNICEF project. In common with the other two teams, the Gomel team had selected 15 families from a large pool of families interviewed to take part in the project. We were to meet two of these at the Centre.



The first mum (not shown), Tatiana, came alone. She told us she had fostered Liosha 3 years ago and was planning adoption. Liosha is a 7 year old wheelchair user who had previously been living in a baby home in Mogilov. Her main problem appeared to be with the practicalities of getting him to School No.72 where he will be educated. They live half an hour away from the school which is a lovely school that was built with disabled access but which is insufficiently funded by the state to provide efficient transport to and from school. There is a school bus but it is not always reliable so she is worried that Liosha may sometimes not get to school. (public transport would require two bus rides and some of the public buses don't have facilities for the disabled). Tatiana's main issue, therefore, revolves around finding out with whom she needs to consult to get support for getting her fostered son into school.

Everyone agrees she has a very positive attitude and would also make a great ambassador for the future fostering project to which we are applying for funding from the British Embassy (as long as she keeps quiet about her desire to foster only a child with physical disabilities!). She told us that she will be very happy to talk to and work with other families in the UNICEF project regarding coping with children with disabilities.

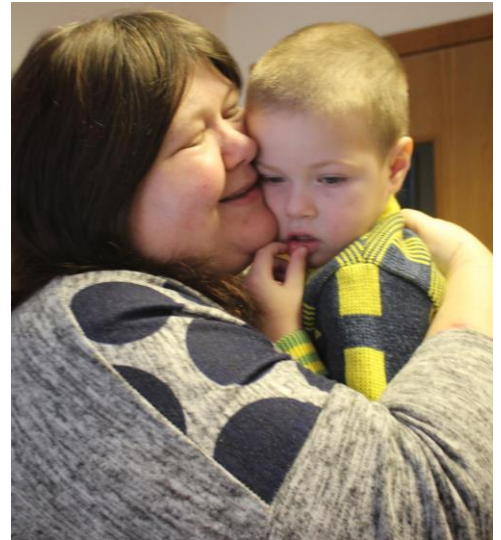
Tatiana is the only one of the 15 families with a foster child, all the others having birth children.

Natasha told about one of these – a tragic story of a single father whose wife had died of cancer 3 months after giving birth to their autistic son. The father couldn't cope with looking after the boy who is non-verbal, now 14 years old, and became addicted to alcohol. Social Protection tried to intervene and take the child away but Natasha got him to bring the child to the Mayflower for a week's respite once a

month and that has given the father the chance to sort himself out. He has now done so, things are better and he has an amnesty from the state. He is positive now and thankful to Mayflower for the help. For me, just this one story illustrates just how worthwhile the setting up of the Mayflower has been and makes me very proud of CCP.



The circumstances of the second mum we met, Olga, and her 3 year old son, shown here, were quite different and extremely distressing. When her son was born all seemed fine, but at 8 months old he suddenly stopped breathing for 40 seconds, turning blue, having to be resuscitated by his mum. These incidents have continued to occur regularly but randomly, as have seizures. She has seen a succession of doctors who are unable to diagnose the cause of the problem and who, instead, keep finding further problems such as twisted arteries and cysts in his head, which have loaded Olga up with yet more worry. Her husband works through the week and at weekend he looks



after their son while she works as a cook. The poor lady is at her wits end and, although smiling for the photo, was agitated and in tears most of the time she was with us. In this case, the main benefit from being a member of the project is the emotional support she receives from attending the “parents club” where she is able to talk to other parents.

SCT Office – Meeting with Nellie, Chief Psychologist for Region, Elena and Liena, Both Psychologists

We next went to SCT’s office in Gomel where we met the three ladies who had taken part in our recent mental health project. Linda informed them that, unfortunately, the British embassy has not agreed to finance the new, small \$2000 project that we had applied for, but that we still have funding that will enable Kay (Child Psychiatrist) and Sally (Clinical Nurse ADHD specialist) to visit in May to provide more training. There followed some discussion about where that training would best be provided.



The ladies told us that they are still keeping in contact with the families that took part in the previous project and were, voluntarily, going to provide psychological support to one of the children during a forthcoming performance they are planning to give.

Next, Linda and I had a discussion with Natasha and Elena Voloshinenko about progress with the UNICEF project. Natasha told us that Prior Bank, one of the large Belarussian banks, had provided all of the funds for the project to UNICEF and that, so far:

- a total of 377 families had been interviewed (in September and October before the project had officially started)

- the complex assessment of each of the families had finished and 15 had been selected in each location.
- a booklet for parents had been completed. The booklet is a statement of what is currently available and informs parents what to do, where to go, what support is available and provides the addresses of correctional centres, polyclinics and explains what the state will and won't provide.

Natasha said that much of the hard work had been done and most of the remaining activities involved working with the selected families. The end result, or “deliverable” of the project is to be a book of case studies, perhaps involving 5 or so of the families in each location, which describes the way the project has been able to help those families through management of their cases, explaining how the teams have worked with the families to improve their situations. It is hoped that a draft of this book will be available for Geoff to scrutinise during his visit in May. Lewis will help all the teams plan their case study work, whilst he is in Belarus this week (Beginning January 28th)

Finally, the discussion turned to the Fostering Projects. Linda asked Natasha to ensure that, between now and the arrival of the experts from Essex in March, there is a lot of liaison with the Rechitsa, Babitchi and Ulookavye orphanages and Gomel Village to identify potential children who might be suitable for fostering. Natasha told us that they were already looking for parents in the Gomel and Rechitsa districts who could potentially foster children with disabilities. Getting a successful result to this project would afford a great start to the proposed next, year-long project on fostering, should we succeed in winning funding from the British Embassy.

Visit to Klimovka



The day finished with a visit to Family Home 2000 at Klimovka where we were warmly welcomed, as always, with a huge spread of food on the table.

Special School No 5

Wednesday started with a visit to School No 5 where we were shown around by the Deputy Head, Natasha, while Aleg, the Director, prepared for inspectors. She was pleased that, through a donation, they had been able to renew about 10% of their old windows with plastic double glazed units, and they had been given sand tables, special chairs for the sensory room and a new washing machine. The donations came about as a result of the publicity generated by a big concert at which some of their children performed in front of television cameras.



beautiful colourful interactive sensory mat which she appeared to love working with. We observed that she has to hold the figures right against her eyes to detect colour, I guess.

Linda invited her and her mum on a holiday to the UK this year and said that she would try to arrange a consultation at Manchester Royal Infirmary for a second opinion, and meetings with special needs teachers who would be able to advise on how best to work with Angelina.

Mum asked whether, if she could get the money from an organisation called “Unihelp”, whether we could arrange an operation in the UK. Linda told her that, really, the best we would realistically be able to offer is an expert second opinion as we suspect an operation in the UK would be extremely expensive.



Visit to Gomel Baby Home

We were joined by Tatiana, the Chief Paediatrician of Gomel Region. The director, Elena, gave us an update on the current situation:

- there are a total of 57 children living at the baby home.
- of which 12 are palliative.
- 31 children were taken from their families last year.
- 16 children were adopted last year.
- 3 children went to foster families.
- 5 children went to family homes.
- 24 children were given back to their birth parents.

The Health Ministry spoke several years ago about a plan to get all reasonably healthy babies fostered instead of coming to the home and then to expand the palliative care expertise at the baby home so that it could eventually become a respite centre – will soon come to fruition. Our Foster Care Project will help with this if we get funding from the British Embassy.



available. In Belarus, the system dictates that a family can only apply for fostering when a child is available and has been selected for them. The registration process can be lengthy which means that the child ends up in the baby home while it waits. This means that, effectively, the quickest way to get a new baby fostered urgently is to foster it

For my benefit, Linda explained that, currently, there is no such thing as an “emergency foster family” or a “temporary foster family” as we have in the UK, who have been pre-prepared and pre-registered for fostering ready for a child becoming



with a family that already has a foster child. Elena considered this to be an unlikely option but Linda pointed out that it is common practice in other regions such as Mogilov, where there have been no new admissions to the baby home for years. Not surprisingly, Elena didn’t show a lot of enthusiasm when Linda told her about the current and (hopefully) forthcoming fostering projects.



This little girl has Butterfly syndrome which means that her skin constantly breaks out into sores. Maybe the Children’s Village could take her but she really is very delicate and has low life expectancy and the Baby Home carers obviously all adore her.

Visit to Ulookavye Boarding Home

by some of the children.

Our visit to Ulookavye commenced with a performance put on

There are 117 children living at the Ulookavye, of which 85 are orphans. They have a pre-school group comprising 17 children.

All of them go to a holiday camp for 20 days in August which is when maintenance work on the building can be carried out. We were given a tour of the building by the director.

We were shown an interactive sand play facility that had been donated to the institution that comprises a computer and projector suspended from the ceiling so that images could be projected onto a tray of sand beneath. We were told that the images would change according to what the children did in the sand below, so providing an interactive effect.



They had the usual craft and sewing rooms and, a room for horticultural teaching and a room with fishes and animals in tanks etc. They have recently had to create a new classroom to accommodate new children, but because they have used up all of their year's funding this was extremely bare, with just a few desks and chairs and a blackboard. They had been donated an interactive whiteboard but had no computer to operate it. Most of the school's computers are old, so we decided that the next Godel transfer should buy them some new ones.



We chatted with the director about the fostering projects but, disappointingly, she seemed not keen on the idea of allowing any of her charges to go to foster families, explaining that she thought that the staff at the home are much better qualified to look after children with special needs than are parents who are essentially untrained. On a positive note, she told us that they are still using their independent living unit which is occupied by different sets of 3 boys and 3 girls on consecutive months, starting February each year and running through to July. Here, the children can try cooking, cleaning and generally looking after themselves. We have run an independent living projects at Ulookvye in the past.

Visit to Godel Technologies, Gomel office

We had a brief visit to Godel Technologies new office in Gomel. This is the company's fourth office in Belarus as it continues to expand.

Timofei seemed enthusiastic about our work and informed us that he, himself had been on a recuperative holiday to Germany when growing up and that his brother had been on many such holidays to Germany. He also told us that his wife is sometimes a "clown" entertaining children in hospital and coming to visit our hospice families, so I'm guessing he has a lot of empathy for what we do.



Visit to Rechitsa Boarding Home

The first visit on Thursday morning was to Rechitsa Boarding Home. We met Victor, the Director, who was very proud to show us the elaborate Christmas decorations that he had had put up all over the building. He happily posed on the very well decorated stage for us.

He confirmed that he would be delighted to have volunteers again this summer and we told him that we were hoping to have enough to be able to send 2 groups this year. At the request of Lynne, I asked him for some details that we could pass on to



the volunteers at the information weekend. Victor told us that there are currently 116 residents at the boarding home, of which exactly half are children. He anticipates being able to send between 18 and 22 children to Ptich and that they will stay there for the whole three weeks. He then gave me the information that I needed for Lynne about the hours that the volunteers would be able to work and where they would stay (a flat near the town centre).



as well as they are here – he cites the fact that he has a 24 hour medical facility on site which wouldn't be the case at a family.

Visit to Education Department Territorial Centre

The main purpose of the visit to the Territorial Centre was to meet the team running the UNICEF project in Rechitsa district. They are shown in the adjacent photograph along with the director of the Centre and to hear about some of the families taking part.



But first we had a discussion with the Director to follow up on the one Linda and Natasha had had with him in November about the possibility of giving some respite care at Dom Dominik House.

This was set up by an Irish Charity, using Klimovka as a model, but aiming to provide a home for more capable physically disabled people. Two of the young people who live there are about to move into their own flat. When they do, the room which comes free, could be used for Respite Care. This would be a great boost to the Unicef project and to all local families with children with disabilities.



Currently there is just one member of staff at Dom Dominik, but there are two young people who are living there who are really too able to be full time residents. They are happy to provide care for a respite programme and would need a salary of just \$100 each, plus their bed and board.

The Director said that 6 months' salary, starting March, would be required to get the process started. Linda agreed to fund the salary for 3 months in the first instance and hopefully for longer if SCT is lucky enough to be implementing partners in the follow-up UNICEF project.

The project team, led by Elena (in blue) told us about 3 families taking part in the UNICEF Project.

Family no. 1 – The project team were able to help a single father of a disabled child by giving him papers that entitled him to larger payment from Social Protection and were also able to organise a baby-sitter for him. They have also shown him how to apply for a sanatorium holiday, all of which he was unaware about.



Family no.2 – a family with a child with a rare condition (only 24 children in the world have the same condition) in which her muscles don't work so has to have lots of special apparatus. The team have

been able to connect her mum with a group of mothers who have helped her with locating sources of specialised equipment as a result of which she has become happier and more settled.

Family no.3 – A 5 year old girl with a degenerative physical disability. The team have shown the mum – who didn't know how to use computers and the internet – how to access help from various sources online. They have also helped rebuild the mum's confidence level which has been shattered by the doctors who initially told her there was nothing seriously wrong with the girl but then revised their opinion to the current diagnosis.

In common with the groups in the other two locations, the Rechitsa team have organised a parents club in which all of the selected families have been enrolled. Regular meetings with other families provide both practical and emotional support to the members of the club.



Visit to Babitchi Boarding Home

The final visit of the day was to Babitchi Boarding Home where we were warmly welcomed by Gregori, the director.





The institution is home to 102 residents (down from 192 residents 12 years ago). Gregori explained that, in the old days, mainstream schools wouldn't take children with even mild disabilities. Now, because of the policy of inclusive education, the mainstream schools have special units to look after children with special needs. So now lots of the children who used to live here have gone back home and go to mainstream schools – hence the reduction in numbers. He said that this is an excellent demonstration of the process of deinstitutionalisation. But, he went on,

not all families actually want this because they prefer to take advantage of the free food and books supplied to their children by the Boarding Home and this is one reason why it is difficult to reduce numbers more quickly. He reported that most of the children come from very poor single parent families and joked that, if Belarus was as rich as the UK, then there wouldn't be a need for boarding homes. He said that some foster parents were returning their children to the boarding home because they couldn't cope. Needless to say, from the discussions, we could see that Gregori was even



more reluctant to participate in the fostering project than the director of the other institutes.



Linda told him that we'd be looking for about 8 children who might be suitable to go to foster homes. Gregori said that he would consult his very experienced social pedagogue (who will be coming to the training which will be delivered by social workers from Essex in March) about finding suitable families. When Natasha suggested that it might be possible to convert

"patronising families" (ones that look after children just at weekends) into fully fledged foster families Gregori responded that most of these are too old to be able to cope with full time care.

Visit to Zhuravichi Boarding Home

Friday morning saw us embark on the long journey to Zhuravichi. We arrived to be very warmly greeted by the lovely director, Natalia, and to be faced with having to consume a huge spread of elevenses.

Some of the rooms appear to have been decorated much more than I remember from last August and not just with Christmas decorations. And it was great to see posters on the young people's bedroom walls.





We visited many of the groups and it was great to see the kitchen which CCP provided with a grant from the US Embassy in use by the young people.

And they enjoyed doing their Christmas performance for us



Visit to Vikov Psycho-neurological Institution

After leaving Zhuravichi, we went on to visit Vikov. The timing allowed only for a brief visit, just enough to have a brief discussion with the chief nurse and to watch a sports completion between some of the more agile residents, staged by Ludmilla. The chief nurse told us that Tamara, the director, had broken her toe and had been off work since the end of December, due back at the end of January. They had lost a cultural organiser and a cultural instructor, both of whom had resigned recently. Ludmilla was still spending



most of her time with the residents on “our” corridor and is being paid 0.5 staff norm from Vikov and 0.75 staff norm from CCP. She does, however work long hours we were told.

Meantime, Natasha the psychologist had voluntarily given up her half time job paid for by Vikov and was now working just half the week for her CCP funding.

Visit to UNICEF Team in Rogachev

The final official visit of the day was to the Territorial Centre in Rogachev to meet the team running the UNICEF project here and also some of the mothers involved in the project who were attending an art-therapy session. The team in Rogacheve is led by our very own Galina Femenok, her colleagues being Anna and Christina. Anna is a defectologist (special needs teacher) who works in the local correctional centre. Christina is Head of Social Adaption and Rehabilitation Centre and works with problem families, abuse and suicide.



They told us about some of the families they are supporting, including a foster family and a guardian family with children with disabilities including cerebral palsy, one of them being non-verbal.



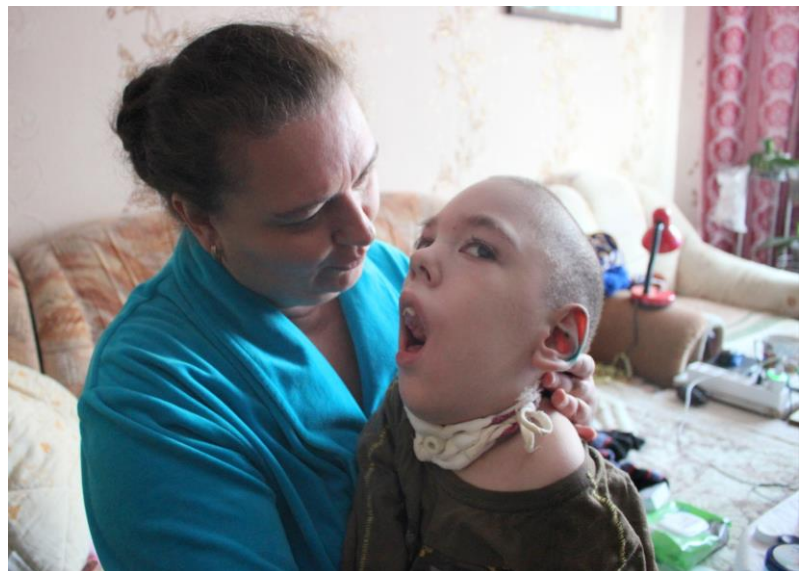
They are able to give greatest support, particularly moral and emotional, to the families who live in the town and particularly those who are able to attend the parents groups at the Centre. But several of the families in the project live in remote villages and cannot attend these meetings. In these cases, Ludmilla (our “Luda”) from Zhuravichi makes visits to their homes to offer support, on a voluntary basis, as well as more occasional visits form the team.

Visit to Rodni Kut

The visit to Rodni Kut was, as always, lovely and we were warmly welcomed by Sergei, Oxanna, Zhanna, Nazar, Anton, Stas and Anya. And we were treated to another performance.



Hospice Family



We commenced our last day in Belarus with a heart-breaking visit to a mum and her palliative son at home. Her 11 year old son had been born a normal looking baby but, a few days after birth he had choked while being fed milk and had stopped breathing for 45 minutes. This led to serious brain injury and he has since grown up in a semi-vegetative state. His father died from stomach cancer a few years later and since then his mum, an incredibly strong lady, has looked after him single-handedly in their flat ever since. He requires the use of a ventilator at night and the frequent pumping out of liquid from his lungs. His mum has, herself, recently had cancer of the thyroid and had to have her thyroid removed. She declares herself ok now and is able to earn money through doing some online accountancy work for a Russian company, the payment for which supplements her benefits. She also spends countless hours doing the most beautiful cross stitch creations. Through the Irish supported charity White Dove, she is able to get a trained baby-sitter to come a couple of times a week to allow her a few hours out of the flat, but is otherwise a prisoner in her home.

Much more cheerful was a brief visit to **Marina and her baby Masha**. Masha was under the weather and had been taken into hospital in the morning with a temperature, but soon sent home again. Marina is happy and confident looking after her.

Gomel Regional Children's Hospital

We then went to visit the brand new Children's Hospital, where we met the Irina, the doctor in charge of our Home Hospice Team, and Slava, who is once again Chief Doctor of the Regional Children's Hospital, having been removed some years ago by the President. We



we were told that the new hospital has 185 doctors over 14 departments and 1000 staff in total. We were



in the new part of the building but the old part has been renovated too, and now comprises a huge hospital. The hospital has almost all of the equipment it needs, including MRI scanners etc. The intensive care department is wonderfully well equipped and we went to have a look. There were 13 children in, and three of them were palliative.

Slava reported that the state has a big plan to buy 300 artificial respirators for use at home which is strange

since there are currently only around 100 children in the whole of Belarus who require them. If the machines are provided to families by the state then the hospital is responsible for servicing them. If families manage to buy their own, or find sponsors to do this for them, then the hospital cannot help with maintenance.

We said goodbye to Natasha and Sasha at the railway station and took the train to Minsk.

Evening Meal with Vera, Olga and Ala

Our final evening in Belarus was spent in a very comfortable restaurant in the suburbs of Minsk, close to the homes of Vera (Head of Institute for Inclusive Education at the Pedagogical University) and Olga and Ala (Paediatric Doctor and Psychologist at a local Polyclinic), all of whom had been on educational exchange visits to the UK in recently years.

Brian Hardwick 24th January 201

