## СНЕRNOBYL CHILDREN'S PROJECT (UK) ПОДДЕРЖКА ДЕТЯМ БЕЛАРУСИ

## Linda's visit to Belarus June 2018

I flew from Manchester and took Sasha back after his holiday in the UK. He was very happy and told anecdotes about his visit to Sasha, our driver, on the way. He was met at the gates of Vasilovka by three of his friends, who were all going to join him for some of the coffee he took back and were looking forward to a Whisky party in the near future.

On Sunday morning Anya and I visited the **Search Club**. The mother of one young man had recently died and he



is going to have to go into an institution as there is no-one else in the family who can look after him. He will go to Terukha which is about an hour's drive away, and is for people with psycho neurological



problems. It is a much better institution than Vikov, but even so it seems sad that he has to go there. I think he is on the autistic spectrum so the poor chap is probably labelled with Schizophrenia. The other young people had clubbed together to buy him a new phone so he can keep in touch and they want to visit him at Terukha.

They showed us videos of some of the things they have been doing since I last saw them late last year.

They also have lots of ambitious plans for exciting days out including getting many of the group on a

day trip to Minsk to go to the War Museum. As we cannot help them with transport to sanatoriums this year as we have often done in the past, I gave them \$160 to help the less well off families with the outing to Minsk. Many of the young people have never been there.

Natasha is a fairly new member of the Search Club and she comes with her husband. At lunch time, when they all give each other Birthday Wishes for anyone who has a birthday this month, she was very emotional about what being part of Search Club meant to her.



Tatiana, the Chief Paediatrician, accompanied us to visit two **Hospice Families** on Sunday afternoon. The first was in a small village quite a way form Gomel and is a very tragic story.



When this little boy was just three months old his mother tried to kill him. She struck him on the head and then threw him on the floor. He did not die but has suffered severe brain damage, has very little awareness and is fed by gastrostomy.

The mother was put in prison, but after a short while it was decided that it



would be better for her to be out of prison and made to look after her child (!) As you can imagine, she does not do that. He is in the care of his great grandmother who is in her late 60s and

his mum seldom visits. The little girl, who is delightful, recently had her fourth Birthday and her mum forgot, didn't come and didn't send a present. Her grandmother is having treatment for cancer. Maybe later she will be able to be involved in the care of the children.

They live in one room, but downstairs there is a larger flat which she can have if she can renovate it. She is trying to do this slowly with little bits of spare money. We are sponsoring this family for £30 a month.







The second family were very different, an extremely caring young couple.

We have a grant from the Hospice in Minsk for \$5,000 which will be used – when it is cleared by the Ministry of Economy – for spreading information about palliative care amongst the medical profession in Gomel region, and for providing consultations to families from neurologists and other specialists.







We visited **School No 5** on Monday morning. The children are on holiday but the school had been instructed to run a summer camp for fifty children for nine days. This was not at the request of parents, and the school had to persuade parents to let their children take part!







Some of the children were taking part in dance and music activities, others were doing woodwork or sewing.

We talked about the visit which we all hoped that Rob from Godel would be making the following Monday, but unfortunately he had to delay this till later in the summer.

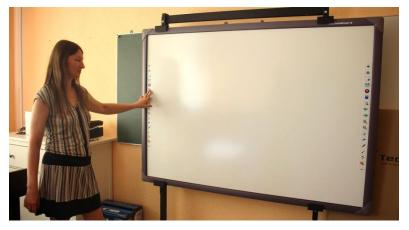






In the group for young autistic children this little boy was putting together 'I want bubbles' with his symbols and giving it to the teacher. After playing with the bubbles he was asking again.

The school had recently hosted a Republican seminar on alternative methods of communication where other schools from around the country were very impressed with their





work. And the interactive white board and projector they had bought with a donation from Godel had been fantastic for this seminar, as well as in everyday use in teaching children.

We had a good meeting with **Piotr Shutko**, **Director of Social Protection**. He was very grateful for his visit to the UK and that he had been thinking a lot about what he had seen. He told us about a hostel in Svetlagorsk, where some people form institutions are going to be able to live, and that he now realises more support is needed from the local social territorial centre. He was very happy for us to provide training at Vikov and to visit anywhere we want. I asked if he will be able to work more closely with Paroshin, the Head of Education in the future. He said they had known each other for a long

time, but that after a week of spending long hours together and discussing what they had seen he was sure their co-operation would be closer than before.

Shutko, on the right, Poroshin and Privalov, the Deputy Governor, during their visit to the UK this spring.



Next stop was **Gomel Baby Home.** There are still about 65 children in the home. Many are being adopted, but children still keep coming in, instead of being fostered straight into families.





The child on the right is from a family of 9 children. The father is in prison, but amazingly Belarusian law allows a couple to spend a few days together every year, and this mother gets pregnant every time. She is having another baby now, so her youngest is in the Baby Home and three others are in an orphanage.



The palliative children spend a lot of time in hospital. I still can't really understand whether the Baby Home is supposed to send them every time they have a temperature or whether Elena is being over cautious. Some of the children who are very poorly all the time and have no quality of life at all, should surely not be revived when their hearts stop, but this is not possible in Belarus. Even though the children are palliative there is a big fuss when one of them dies in the Baby Home.

Elena told us about an eight and a half year old who is currently in the hospital. She said she should not be keeping this child in the Baby Home. Although the law has changed so that children on ventilators can stay in a Baby Home throughout their lives, for other palliative kids it is just till their 8<sup>th</sup> Birthday. The child should be going into the care of Social Protection and Education should be attempting to teach her. But her health is very frail and she is in and out of hospital.

We talked to Shutko about this. He said if Elena wrote him a letter about the child, her condition and why she should stay in the Baby Home he would write back with his agreement. If the agreement of Education is also needed I am sure Natasha can organise this without difficulty.

At the Mayflower Centre one of the young men staying for respite was Gera who gave me a friendly wave. I realised that I had seen him in the centre several times when he was young, but not in recent years. This picture was taken 11 years ago, and is with the same carer, Alexandra.



Yanna came to have a chat with us. She has been teaching the young people from the Robinson's Group to use the computer. Godel gave us two computers for use at the Mayflower Centre about 2 years ago, and Yanna has worked since then. We pay her unofficially and just 120 roubles a month (\$60). She has managed to teach many young people who the staff never expected to be able to learn



computer skills, and she loves the job. Her face was shining with enthusiasm when she spoke about how she loves to teach, and especially the moment when she realises that her student has really understood what she is trying to teach them. It would be great if we were able to employ her properly in the future. She has quite severe physical disability which does not affect her hands but she walks on crutches and with great difficulty.

Natasha agreed that she would come to Zhuravichi and Vikov with us on the Wednesday to make plans for delivering training for the sanitary staff at Vikov.

At **Duyanovka** we just had a short talk with Vigera, the Director, who was not looking well. Duyanovka is now a psychoneurological institution and all the more capable residents have been moved elsewhere. Just Sasha Baikesh, of all those we know remains at Duyanovka. He has a slight learning disability, but his main problem is very poor hearing. He was staying at Klimovka last week, and will visit there regularly when no-one else is staying.











The young people at **Klimovka** were missing Marina and her baby Masha. Ira and Greesha in particular had adored Masha and were looking forward to her coming back to visit. I agreed that Marina and the baby should join them for the sanatorium holiday in August.

Liena was due to go to hospital for her regular check up and treatment so Larissa will organise for her to go next month. On Tuesday we went to visit **Rechitsa Boarding Home**, where Victor was welcoming and had even had a pizza made for us this time! In the past he never used to give us a cup of tea.

Only 23 children will be allowed to go to the sanatorium this summer, so that means that about fifteen children and lots of young adults will be at Rechitsa all summer. It would be great if we could send some volunteers as we did last year. It may be that a group can go for a few days.

Last year they also had Belarusian volunteers from World without Borders but Victor says they have not spoken yet about sending anyone this year.



We visited **Kapatkevichi Institution** which is just a few kilometres from Ptich Sanatorium, and had a long talk with the Director, Ludmilla.

This is a home for people who are either elderly or physically disabled, just as Duyanovka was until very recently. But it is run so differently.

Ludmilla expects all her staff to treat all residents with respect. The doctor is responsible for the way the nursing staff work. And the nurses teach the sanitary staff how to turn people, feed them, wash them, and to encourage residents to ask for help when they need it. They are expected to keep a written record



about any problems or issues which occur. There is a five minute meeting every morning between the night shift and the day shift to pass on all necessary info as they hand over.

They take people on lots of excursions in the local area. And they regularly take people to Gomel for medical treatment or assessment as it is better in Gomel at the Regional Hospital than the nearby hospitals. I am not sure how they are allowed to do this as it is a good two hour journey by car, so longer by minibus. When it is not urgent they wait to three or four people who need to go for an assessment so they can go together.

We talked about taking some of the young people to Ptich for day visits when the volunteers are there. Ludmilla thinks there are about fifteen young people who could and would want to go. She will ask the doctor to check out their needs and see who would benefit from the health procedures carried out at Ptich and who would just enjoy the holiday experience. Then we will work out a plan and she can organise the transport to take them back and forth.



Natasha stayed in the office on Wednesday to complete some urgent paperwork, but Natasha Semenyako from

Mayflower came with me and Anya to **Zhuravichi.** 

Natalia, the Director, was very sad and was on the verge of tears on a number of

occasions. Very soon the last of her children will be gone and Zhuravichi will be an adult only institution.



As you walk round the building most of the walls are adorned with Nastya's paintings or pictures by this young man, known to the volunteers as Italian boy as he speaks Italian well after many holidays there.



Some of the girls were busy preparing costumes for a talent contest between the institutions which



was due to take place at Duyanovka.

Inna, Luda and Sveta (who teaches cookery and life skills) can all be retained half time as instructors for the young adults. I said we would continue to pay Inna and Luda half time as before, but could not promise about Sveta.

We had a very positive visit to **Vikov Boarding Home**. Last autumn a new Director, Natalia, was appointed. She was lovely and very enthusiastic about co-operation with us,

training for her staff and input from volunteers. It had been a shock to learn that she is pregnant and



on maternity leave already.

But the interim Director is just as great, and has a lot more experience than Natalia. When we discussed the possibility of Natasha delivering some training for sanitary staff and I asked if she would want this she put both hands up to show her enthusiasm. Natasha will liaise with her and the psychologist and go to do a first training session very soon. SAnya met the old chap she has adopted as a pen pal and he had a long letter for her which she was delighted with. Lots of people were sitting out in the sunshine which always makes things feel a little better. The first old lady wanted a picture on her own, so they all demanded one, as did many others.



in the training so she can carry on with some further sessions.

She and the Director asked for more materials to enable people to be active, particularly outside. I said I was sure the volunteers would bring lots of good games and could leave them when they go home. Zhuravichi is relatively well equipped, so it would be good to leave most of the stuff at Vikov.

At **Rodni Kut** the atmosphere was happy and positive.

They had been to the Centre in the morning to listen to music and join in with dancing and were outside enjoying some sunshine when we arrived. They are still going swimming every couple of weeks and Katya, the art teacher comes once a month.

Sveta, who comes to teach the young people showed me a photo report of lots of their activities.







For the first time I can remember they were all praising Nazar for his memory and use of language instead of criticising him for what he can't do. They said Anya in her head is already in England! She has had two small seizures which they have noted down to tell Joan about. People in the shops they visit save small empty boxes for Stas as they know how much he loves them.

We finished the day with a very pleasant evening with Galina Femenok who is involved in all the work we do on fostering; is currently working on a big project funded by the Hospice and Health Prom; and will be a consultant for the UNICEF project if and when this gets off the ground.



On Thursday morning before setting off for Minsk we had a long meeting with Elena Voloshinenko, mostly about the UNICEF project.



This was first discussed when I visited last November. Then in late January several people from Unicef came to Gomel and Natasha organised their visit to various institutions and to meet officials. There was another Unicef visit to Gomel in the spring and Geoff and Natasha spent two days travelling round with them. The project has been written and amended several times, but hopefully will be ready soon. The plan is to support families with children with disabilities, organising child centred

assessments and care planning for them.

On the way to Minsk we called in to see **Marina.** This is the young woman who was living at Vasilovka, where Sasha lives, until she became pregnant. She wanted to keep the baby so she was chucked out and landed at Duyanovka. Vigera was distraught as she was not allowed to be there either. She stayed at Klimovka for a while; Shutko promised that Social Protection would find her a flat; and then she went to a Mother and Baby shelter in a church in Bobrusk. Only it turns out that they do not yet have a licence to provide a shelter,



so on the day we called Marina was packing and was due to be taken back to Klimovka. Greesha will be delighted. She is still breast feeding and is doing a good job looking after Masha. The flat she has been given is near a centre run by Vera who used to work at Ulookavye, so Natasha will be able to ask Vera to keep an eye on her and see if she needs support.

In the evening Natasha and I attended the Queen's Birthday Garden Party with Valentina. I had hoped it might be a good place to meet people but with hundreds there it was only really possible to meet

people we already knew. The nicest moment was when I bumped into Schasny, who was the Ambassador in London twenty years ago. He spoke at our conference in Leeds alongside Sasha. And he apologised to Sasha for the way Belarus had treated him. He still remembers this and says he often mentions Sasha when he has to give a speech!



On Friday morning after the meeting at

Unicef, we went to visit Children in Trouble. Elena and Nastya were full of stories about the horrors of working with the British Visa services. They say there is no other country like it. It is still simple to get visas for Italy and Germany. They are still free and only children over 12 are fingerprinted and then only every five years.

Nastya went to the Embassy with the group going to Glossop. One mother has a child who is less than six months old. Nastya said they spent half an hour trying to get a picture they were satisfied with of this baby. And then when the mother was on the way home they called her back to do it again! And it costs £100 to get a visa for a baby.

At the Visa Application Centre in Minsk the rules are constantly changed – they want original documents, then you must bring only copies; you need to bring a photograph of the child, then you don't, then you do again. If you ask them a question they say 'look it up on the website' You go back and say it is not on the website and they just tell you to look again. Eventually they gave Nastya a sheet which says if you want to ask a question you can send an email to this address but it costs more than £5 to send the email. And it is probably an Indian call centre where they won't know the answer anyway.

All our application forms have been submitted and the last groups will be at the VAC this week to submit their documents and passports.

It is completely impossible this year for 18 year olds to come if they want to go to University. The universities have got stricter about having the passport with you rather than a copy and applications must be made when the passports are at the Embassy. They told me about one girl in the Endon group whose mother died and the local social services tracked down the alcoholic father who is in his late sixties and said 'you must look after your children'. So the poor girl must live in really awful circumstances. There were lots of teens they wanted to send to Endon who were not allowed to go. In some cases a doctor said Yes, then the doctor who was going to accompany them said No, and then there was a further consultation. Some were allowed and some not. They mostly have sarcomas.

Most of the Solihull group have had bone marrow transplants so Elena said they should not have as active a programme as usual as they will get tired very easily.



At Barovliani these two teenagers had just joined Children in Trouble. Angela, one of the teachers there, had a good stack of new applications and she said the photo book was a big help.

In the Rehabilitation Department a doctor came to see me at Evgeny's request. She said 'Dear Linda. We have some children who need a very specific medicine' and my heart sank as I felt sure we would not be able to help. 'Only a small number of children need it, so the Ministry won't register it. But it is very important for these children and it can be bought in Russia'. I said we did not have spare money at the moment but perhaps we could do a special appeal. How much is the medicine? When I heard \$150 mentioned I thought it might be \$150 a vial.

But it turns out these are tablets. They could treat the children who need it urgently for \$150 but \$300 worth would be better. I was very happy to give them \$300.

At the Hospice Natasha and I talked with Anna and Pavel, the doctor who organises the grant



programmes, about the small grant Natasha has just got from them, and about the big EU grant they have submitted a concept note for. They should hear soon if this has been successful and then they will move on to the next phase of a major application with the Hospice as lead applicants and 'World Without Borders' and SCT as co-applicants.



In the garden of the Palliative Care Centre was the most amazing creation. Working with just clay and a curved knife this man has made a fairy tale world. Try enlarging this page and looking at the tree. It is so hard to believe it is not a living tree. I thought it must be costing them thousands but he is doing it as a volunteer!

Saturday was the day of the Great British Festival which took place in Minsk Old Town.



Thousands of people were milling around the area and the promised rain did not materialise. Our stall had plenty of visitors who included Inna who came to Glossop as interpreter in 2000; Vadim, who stayed for many years with Barbara Cox; and Tamara (?) who was a friend of Geoff's in the 1990's. A number of young people volunteered to interpret for us in Minsk when we have visitors. If we do it again next year we will make sure we have an activity to draw people to the stall.







