

CHERNOBYL CHILDREN'S PROJECT (UK)

ПОДДЕРЖКА ДЕТЯМ БЕЛАРУСИ

Visit to Belarus January 2020

My first visit was to meet the new **British Ambassador**, Jacqueline Perkins. She was very welcoming and interested in our projects. I will send her the application which I sent last year and was rejected as not being sufficiently about 'human rights', to see whether there is any chance of getting funding for it this year. Would be good for Geoff to go to see her too when he next visits.

I then went to see **Anna Gorchakova** at the **Hospice**. Their most recent project is to support teenagers and young adults from the moment they are diagnosed with cancer. The World Health Organisation and others now define palliative care more broadly, as being support for anyone with a life threatening illness.

There is a new doctor at the Hospice working on this programme, Anastassia, who speaks good English. Anna would like help with developing guidelines about transition – both from paediatric to adult care, and from active cancer treatment to palliative care. Initially I can ask Francis House and Martin House if they have documents about this which could be shared. But it would be very good at some point to bring Anastassia on a visit if the Hospices would have her, as she could come on her own and stay with a family so the costs would be minimal.

I was collected from the Hospice by Vera who is the Head of Children in Trouble, Nastya and Valentina, and we went to the **Children's Cancer Hospital**.

We spent some time with Larisa, who had organised an Old New Year event for the children the previous day.

She showed us pictures of the Christmas presents who had bought for the children with money we sent in December.



And she told us 'Image Therapy'. Photographers come to the hospital and take pictures of children and teenagers dressed up in all sorts of fancy clothes, which they think makes them feel more positive about themselves and their future.

We visited some of the children and teenagers who are currently having treatment but who we hope may be able to come for a holiday next summer.

In Gomel the next day at **School No 5** we were joined by a young woman, Liena, who has good English and is interested in doing some work for us when we need her. She has been at home for a couple of years with her young daughter and is just about to start work in the afternoons teaching English at the University. She was very nice and easy to work with.



Aleg and Natasha told us that they had recently met the new Governor of the Region, who had promised to do something to improve their heating and the tarmac paths around the school. They said they have many new children and the majority of them have a diagnosis of autism.



This boy produces the most amazing cartoon figures from plastiscine (enlarge the page to look!)



They were very proud that they had created an app which can be used on a tablet for children to communicate. They can say 'I want' and then chose an item, or choose a category and then from that choose an item.



Natasha was very keen that I report back to Pictor school that they are doing their best to develop their work with autistic children.

Our wonderful supporters Godel Technologies have since bought 10 tablets with shockproof protective covers for use in the school.



They told me that the minibus was struggling on OK, but the next day it broke down so I gave the \$200 needed to get the vehicle back on the road and children going to school.

At **Rechitsa Boarding Home** Victor was very welcoming, and told us how much he appreciated the visit of volunteers in the summer.

They have a Jacuzzi type bath which they can't use for much of the year as the room is too cold. He wants to put in a radiator and bring heat from the floor above and needs maximum of \$500 for this. It struck me as a good thing to help with if we could.

They also have a swimming pool which they have finished building but do not have the money to put in the heating and filtration system. This will cost \$8,000. I hope someone will be able to help them with this as swimming is such important exercise, and a wonderful experience, for children and young people with cerebral palsy.

The whole school was covered in Christmas decorations in every corridor and classroom. This was the backdrop to the stage.



Adam had just had an operation on his leg so was in a wheelchair. He is still getting a lot of visits from his family and seems very cheerful.

There was an attractive display about the rights of the child and the rights of people with disabilities. The one below says 'I want to live with a Mum and Dad. This is my right' I am not sure what to think about that, as it just can't happen for everyone.



Allessia, who came to Alder Hey for an operation ten years ago, is still healthy and is now 20 years old. I gave her best wishes from Marion Stoddart and family who hosted her in Liverpool and still take an interest in how she is getting on.



assured that she spends time out and about now.

The home is now 50/50 children and adults, but it won't be long before it is a purely adult institution.



Inga was in a cot as usual but she was at least on a more cheerful room with other children, (also in bed for 'teecki chas' or quiet hour) and we were



Tatiana, the **Regional Chief Paediatrician**, (right) came with us to the **Baby Home** to discuss the Unicef Project. It is clear that the Ministry of Health really want this to happen now – Baby Homes to be transformed into Palliative Care Centres. Our project will help to speed up a process which will happen over the next few years anyway. It will involve three groups of staff – working with the children in the Home and their parents to see if some can be returned home; working with ‘Socially Dangerous’ families to see if



they can be helped to safely keep their children; and with foster families.

We had been talking to Elena, the Director, (left) about this for several years and she is keen to help the project to work as effectively as possible.

We hope that the Palliative Care office, where support for children in the



community will be organised, can be moved into the Baby Home within the year. Then three of the Baby Home nurses will probably be employed in this office.

Liena, (right) the interpreter who had accompanied us the day before, spent a second day with us.

At the **Regional Children’s Hospital** we met Ludmilla, the new doctor who is officially in charge of palliative care for Gomel region, and Aliona, the psychologist who works with her, and is also employed by the Belarusian Children’s Hospice. Aliona is the daughter of Larissa and Sasha at Klimovka, and used to work there too before she trained as a psychologist.



Ludmilla is a Re-abilatologist, working with disabled children, for her main job, and then has a part time, low paid job as Chief Palliative care Doctor. Natasha and I decided that we should employ her for six months initially to expand the work she is doing for hospice families both in Gomel and outside the city.





him, and proud of their achievement in looking after him. They also look after a boy with Down Syndrome and another with learning disabilities, sometimes in their own homes and sometimes at Dom Dominic.

The **Respite Project at Rechitsa** which one of our Trustees, Brian Hardwick, is sponsoring is a great success. When Olga and Maxim arrive at the flat Vanya gets very excited. It was clear that he loves their visits and that they are genuinely fond of



Olga and Maxim both have a mild learning disability, but they have a very responsible attitude to the young people they look after.

At the **Mayflower Centre** there were some old and new faces. The two carers were amongst those who have been there since the very beginning, and Marina, in the green top, studied in our wheelchair class at School No 5 for 9 years. But some of the other young people staying were new to Mayflower.

There is a craft teacher who works with the Robinsons Group and those staying at Mayflower and she was doing some clay modelling with the young people. There is a Centre for Inclusive Culture nearby and some of the Robinsons young people go there sometimes to take part in activities. There is a cut off point for Robinsons – 35 I think – and they can go to this other centre for a little longer. After that there is a long gap before they can take part in services for older people.

Mayflower celebrates its fifteenth anniversary later this year.





Ira and Greesha were very happy to have Liena on the mend. And they were also pleased to have visitors from Kapatkevichi, a home near Ptich Sanatorium.

In the evening we visited **Klimovka** where it was great to see Liena looking and feeling very much better after the stroke she suffered in October. Her pressure sores have mostly healed up at the moment and her speech is almost back to normal. She still has very little use of her right hand.



Maxim, who used to live at Duyanovka, is a very frequent visitor to Klimovka, but Lilia had never been before. She had made friends with them all at Ptich and was delighted to be spending more time with them. She is very excited that she will be going to Minsk for five months from February to study IT skills.

Larissa is trying to find another member of staff who can give Liena the personal care she needs.



The following week Natasha was due to make an appointment for Liena to visit Ruslan, a lovely urology doctor in Gomel who we worked with about ten years ago when we delivered a Urodynamic testing machine. Hopefully he will assess the state of her kidneys and advise us about how best to prolong their function.



At **Zhuravichi** the new Director, Olga, had to be away most of the morning and we only saw her for a brief chat on the way to Rogachev. We were greeted and shown round by Natasha, the Deputy.

She took us first to the Department of Supported Living. I am not sure how much preparation for possible independent life happens here but at least the young people

have more space, individually decorated rooms and more freedom. They can rest when they like, play football and other games when they want to and have quite a bit of freedom to roam around the building.

Vadim, on the right, is one young man who we had hoped to help into independence but he really doesn't want it. He is not motivated to make any changes, and prefers to hang out with his friends and take part in sports competitions when he can.

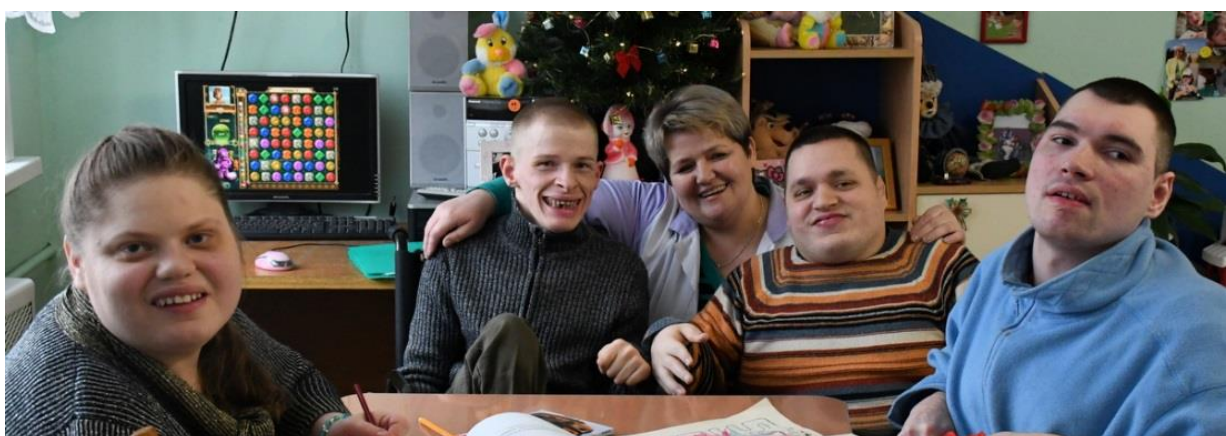


Sergei used to live at Zhuravichi long ago and then we managed to get him moved to Vasilovka. But Vasilovka is a home for people of normal intellect and they tried to get the rights of all their residents returned to them, but this did not work for Sergei. He was declared 'incapable' by the psychiatric assessment team, so was no longer allowed to live at Vasilovka. He seems quite happy back at Zhuravichi.

Inna's group were very pleased to see me and said they had been worrying about my health and wished

me to stay strong and healthy for ever, in the effusive Belarusian way. (They had heard about my new hip). We sponsor Inna to work an extra 20 hours a week.

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visit

Vikov was a delight considering what a depressing place it used to be.

Ludmilla is working for us as a psychologist now, as well as her job as a cultural organiser. After a chat with Tamara we watched a short concert.



Victor recently had an operation on his throat so was not allowed to sing. But that did not stop him miming enthusiastically through all the songs.

Many of the residents were in the hall to watch and enjoy the singing and dancing. They must also be delighted with the artwork on many of the walls.

There are some very talented sanitary staff at Vikov whose wonderful paintings and murals adorn the corridors, communal spaces and many bedrooms.



Tamara has created such a positive atmosphere and so many changes it is quite remarkable. They have a big greenhouse put up by an Italian charity, where many residents help to grow food.

She has set up a sewing room where they make bedding, tea towels etc. This is the teacher as most of those who participate were still at the concert.



And the residents obviously really like and respect her. This guy, who had been one of the singers in the concert, said if she was allowed to stay as their Director he would kiss her hands and feet.

Couples are allowed to live together and people can decorate their rooms as they like.

When we visited **Rodni Kut** there was a lot to catch up with as I had not visited for a year.

We discussed various practical problems like the need for a new cooker and washing machine and then look at lots of photos of the young people taking part in local activities.



The ancient boiler which used to keep the old part of the house warm, had given up the ghost last summer. So now the whole house is heated from one boiler and some of the bedrooms were redecorated whilst the plumbing work was going on.



At the weekend I visited the **Search Club** where a group of school students were doing a performance for them. They had a lot of news about all their activities. They have a dream, says Maria, the psychologist who works with them, to go to St Petersburg. But she has already checked this out when she went on a visit there, and the hotel, food and excursions would cost \$500 each, plus the train travel. I think this project may be too ambitious and remain just a dream

Sasha brought Greesha, Maxim and Lilia to Search Club and they really enjoyed it. Some of the group hope to visit Klimovka again soon to see Liena.



Sveta Lappo came to visit me at the flat. She is still running her animal charity but also does lots of wonderful voluntary work visiting four psychoneurological institutions in the area. She says many of her volunteers who used to say they didn't like people, only animals, never say that after visiting these places. They take some animals with them for people to stroke and cuddle.

At the moment she is working in a supermarket, but is just about to set up her own business organising parties and events. She will be working with friends who are musicians, magicians, etc. and I am sure she will make a success of it.

I had a visit in the evening to the **Diabetic Association** to see pictures of their activities and hear about their problems. If only we could start a new group perhaps we could persuade them to take some diabetic kids. It would be great to offer this support again.

Sunday was spent visiting **Hospice families** with Irina, Marina (one of the nurses) Natasha and the new doctor Ludmilla.



This little boy is on a ventilator and gets very good care from his young parents.

This girl is 13 and has a degenerative muscle disease. Her mum was helping her walk by nudging her feet along. Ludmilla told her that it is possible to get two sets of shoes attached to each other, so this can be done much more comfortably for mother and child.

Irina Kalmanovich, our Hospice Doctor, is about to retire from Palliative work, after ten years of giving wonderful support to children and their parents. She will continue to work

in the Intensive Care Department of Gomel Regional Children's Hospital.

