

Visit to Belarus February 2018

Linda Walker, Lynne Murphy and Brian Hardwick

We flew from Manchester via Amsterdam and spent the first night in Minsk. Evgeny from **Children in Trouble** picked us up in the morning, with Valentina and Nastya.

Nastya had been working on the leaflet for families at the hospital. The pictures were not very clear and much of the information was too large and spaced out. Lynne said her father could print it, and I have sent Nastya some more pictures. Maybe when she sends it to us we could send it to Anya in Gomel to work on before we print it. Frustratingly, the photo book for the hospital arrived in Glossop the day we were at the hospital so it will have to go out in March. I will look out for a special offer and print a couple more.

We talked in the minibus about Gloucester, and possibly Leeds, funding some children who cannot come to the UK for a holiday, to have a 24 day holiday at Nadezhda Sanatorium.

The children go in a group with a doctor and group leader/teacher, just as when they travel abroad. It costs \$25 a day to stay at Nadezhda, currently about £18. Holidays are usually a standard 24 days. So the holiday for a group of ten children and two adults would cost about £5,000.

Nastya has an ambitious plan to set up a website so she can appeal for funds and build some holiday cabins, like the ones outside the hospital. We will see what comes of that, but in the meantime it would be good for groups who cannot bring children to the UK this year, to help to provide a holiday for some of those kids whose health condition means



they cannot travel anyway. *(The picture is Rechitsa kids at Nadezhda in 2014)*



In the **Children's Cancer Hospital** we went to talk to Larisa as usual and she gave us the great news that Belarusian charities are now providing some support for families which means there is no longer the need for us to leave two or three hundred dollars, as I usually do.

Larisa has always used

this for poor families or kids with no parents, to buy them some extras to make their time in hospital a little easier, but the Belarusian charities are now able to supply everything she asks for.

This 14 year old girl who was just stating her treatment spoke quite good English so Lynne asked if she would like to receive some letters from England. Vika seemed very pleased at the idea so Lynne will write to her.





These were two of the teenagers we met who we hope will come to Endon and Stoke either this summer or next. Larissa was making sure that all the families knew about Children in Trouble and would join.

At the **Belarusian Children's Hospice** we met Anna Gorchakova who was as lively and energetic as ever.



She is involved in a number of new projects, with funding from UNICEF and the E.U. She says that Palliative care really is spreading around the country now, at varying levels of ability and she feels that she and her team can branch out slightly into other

areas. She told us that the World Health Organisation have redefined Palliative Care. I just looked it up and the first para reads '*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with **life-threatening illness**, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*'

So they are now talking about life threatening illness, like cancer, rather than life limiting illness. The project Anna would like to set up for teenagers would be respite care for older kids and young adults with cancer, not necessarily for those we would normally consider to be palliative.

When Natasha arrived Anna said that she would like SCT to be involved in handling the fostering aspect of a huge project. Natasha will meet 'World without Borders' next week to find out about this big budget project and see whether it is something we could do.

We met Natalia at **UNICEF** to follow up on the work Geoff and Natasha had done with them a couple of weeks earlier. We were joined by Alexander Karankevich, who I have known for a long time, and they talked about a visit to the UK. They wanted me to organise a visit for a huge group, adding reps of Ministries to the group we are planning from Gomel Executive Committee. I did not think it would be practical and Natalia said that they had sent a group of 65 people on an educational visit to Italy. That must have been organised by a team of people who split them up into small groups.

Lynne explained that at her school even the group I was planning of three people plus interpreter would be considered a large group and would have to divide into two if they wanted to observe classes. We left it that maybe we could add two extra people from Minsk but I have since written to Natalia to say we don't want to do this.

When she talked about the visits they had made in Gomel Region with Natasha and Geoff, Natalia said the rehabilitation work with children and young people was better in Rechitsa than Zhuravichi (true as they have more resources and better qualified staff), but she also said that the residents at Rechitsa were more 'organically brain damaged' than those at Zhuravichi. At first we just thought she had made a mistake and got them the wrong way round but she was insistent that this was true, and said their expert consultant had said this.

We tried to impress upon her that Lynne had spent two weeks in Zhuravichi for the last five or six summers and she could categorically say that the majority of residents at Zhuravichi had far more serious mental disability than most of those at Rechitsa. Natalia would not believe it and preferred to think that their two hours in each place – where they had been shown the girls doing crafts, young people learning to cook and a short concert – was enough for them to know best. Lynne was seriously unimpressed!

Anyway, Natasha will be in Minsk early next week to finalise the project details and then she can apply to the DHA to register it. I guess that will take a couple of weeks and then Unicef will transfer the money to SCT and they have to clear it before the project can begin.

Following the meeting at DHA we travelled by minibus to Gomel, where our first visit the next morning was with Shutko, the **Regional Director of Social Protection**. He was very friendly and positive and interested in our new project. When talked about the new Director at Vikov and told him that Brian was going to sponsor the salary of a half time psychologist, and we were planning to give some training to the staff. And we asked if there was any chance of changing the norms in adult institutions so they could have carers to look after the more disabled people, instead of 'sanitarki', whose role it to wash – floors, toilets, people. He said that there was some discussion about changing the norms, which sounds hopeful.

At the Regional Diagnostic Centre we talked with Tatiana, the Director, who had spent a couple of days in Lynne's school.

There seems to be great emphasis at the moment on including children with autism in mainstream school. This is strange as they are more difficult to include than most other disabilities, and for a many it would simply be impossible.



Many of the children taught in the Centre are autistic and they seem to do a good job with them. They are using symbols widely for communication, and although it is not as developed as it would be in an English school, they obviously learn something new from all the trainings we have delivered there, as well at Tatiana's visit, and adapt it into their work.





We had a lovely visit to **Masha**, who is very happy at home with Polina, although Lynne says she is missing work and looking forward to coming back when she can.

In the evening we visited the **Diabetic Association**. They took Lynne and Brian on the usual tour to show all the work they had done to their office. We talked about

problems with insulin and how over 18s had to buy all their own strips.

They were very excited when they realised that Lynne had lived with diabetes for 40 years and had two children and a good job, and had then had a kidney and pancreas transplant. This rare, difficult and expensive operation had freed Lynne of diabetes. She had to tell her life story to Liena and the Association made her an Honorary Member and are telling all their members and supporters about her.



At Gomel Baby Home Elena, the Director, seemed quite tired and depressed, so I did not press her this time about fostering the children. I asked if she had any who need a gastrostomy fitted and she said that the last child to have one fitted had become ill after a spell in the Children's Hospital and had



to have it removed. This seemed to have put her off having any more children operated on at the moment.

We visited one group of reasonably healthy children (who really should all be in foster families!), one with disabilities and the palliative group.

At School No 5 we passed to Aleg, the Director, the final \$1,000 of Godel money for repairs to the minibus. Aleg says that the minibus is really on its last legs (last wheels?!) and they are going to need a new one soon. He had laughed at Natasha's story about me saying 'Can't pay, won't pay at the Humanitarian Affairs Department, so I said I wouldn't put it quite like that to him, but we could not



get them another vehicle unless we were able to get a grant from somewhere and we need to get one for Rodni Kut first. (We had lunch with Zhanna, the Deputy Director of Education for the region, and I asked her if there was any chance the Education Department could get them a minibus. She said it was not possible this year, but they should be able to put it in the budget for next January. We will have to keep reminding her about this.

Lynne was very pleased to see how much they were using symbols for communication and was quite impressed at their work with autistic children. They have far less resources than the Centre we had visited the day before but they seem to find a way to work with the children. The atmosphere in the school is so warm and caring from the Director and his deputies down, and Lynne and Brian loved it.



The boy on the left in the picture below hid his face when we came in. Yet, amazingly the staff were not only able to persuade him to uncover his eyes and interact with us, but when we left he said he wanted us to stay.



After a fabulous four course lunch with Zhanna from Education, all paid for by her, we visited **Mayflower Centre** where we talked to Natasha about training the sanitary workers at Vikov and interviewing potential psychologists there with our Natasha. We also discussed the new UNICEF project. It is possible that Natasha and one of her team might share the role of social worker / team leader for staff working with families in the Zhelezdanarozhny District of Gomel. What is required is very similar to the work they are already doing with families.



This little chap was staying at Mayflower with his brother. They looked an angelic little pair when they were tucked up in bed, but I suspect he can be quite a handful.

Yanna is once again teaching computer studies to the young people from



the Search Club. We watched her leaving on crutches in the snow and ice and it was painful to see. She travels back and forth on public transport which is very brave with severe cerebral palsy.

We had a lovely evening at **Klimovka**. It was (papa) Sasha's birthday and Larissa had made lots of lovely food to celebrate. The young people clearly love them both and Liena gave a beautiful toast which included a poem she had written herself.

Ira Marcenko always comes with us when we visit. She is a very capable and independent young woman working in our office and at Mayflower Centre, but she never forgets her friends at Klimovka, and what they did for her when she



first left Rechitsa Boarding Home.



Marina has been staying at Klimovka during her pregnancy, but as you read in Geoff's report, she now has the chance to go to a Mother and Baby Hostel in Bobrusk and she will move there next week. The tensions in the house had arisen I think because Marina did not treat the other young people with the respect which Larissa thought they deserved. We didn't feel any tension on the night we were there though and had a very happy evening.

At Zhuravichi Natalia was very pleased to see us all. She had made a great fuss of the volunteers in the summer – keeping them eating and drinking when they wanted to spend time with the young people on the last day, much to Lynne's frustration, but with the best of intentions. We had a discussion about the UNICEF visit and Natalia told us she will soon lose all her children. Three were going to leave the next day and the rest in September. Half will move to the Caritas built Gomel Children's Home which will be lovely and the less disabled ones will go to Rechitsa. Natasha wanted us to try to persuade Social Protection to let her keep some children but I don't think that is going to happen. The important thing is to try to stop her losing too many staff.

The norms allow for no teachers, no carers, less staff in total and they would just be Sanitarki. Any of the carers who stay on a sanitarki will see their pay cut from \$250 a month to about \$150.

At the moment we fund Luda who is a teacher and Inna, a higher level carer, for half time posts, on top of the full time job they have at Zhuravichi. I think it is likely that Luda will leave, but we absolutely must keep Inna there. She does such a tremendous job with the young people in her group. I would like to propose that on top of continuing to pay her a half time post, we also give her \$100 a month (maybe in cash) to make up for her main job switching to a sanitary post.



We have been funding the carer who teaches the young adults to cook, through the US grant. Natasha is very keen that we try to fund her to continue working on developing life skills if we can find a way to do that.

At the same time we will be lobbying to change the norms and I will write to Deputy Minister Rumak to urge him to look at the issue again.



It was great to watch Lynne interacting with some of the young people at Zhuravichi. This lad is deeply autistic and the carer said he does not speak. But within two minutes of Lynne sitting next to him and copying his finger movements he started to say



the names of people and places. Lynne repeated them all and he kept coming up with names. But there is one carer looking after about 20 young people, so no chance of him giving this young man any individual attention.



It is always obvious that the young people love Natalia and it is great that she has such a good relationship with Natasha

And Brian has clearly learned a lot from volunteering at Pictor and from his time spent at Zhuravichi.



This little girl usually stares vacantly all the time. I had not seen her smile in recent years, but it took Brian about three minutes to bring a lovely smile to her face.



He gets on really well with the lads too. The young man on the right took Brian's wallet in 2016, just before the volunteers were due to leave, causing a bit of a panic, but he soon gave it back.



The girls who do all the crafts, and one of two boys also, were making tea towels. These were really nice and we thought we could sell them. Lynne has some to sell at school and Natasha will bring some in March. We could also ask them to make pillow cases and bags if we choose the material in Rogachev.

We had to spend a few minutes watching a concert. It was exactly the same

as the one I saw last November and Geoff and UNICEF had watched it a couple of weeks ago, helping to give the impression

of capable young people, unlike these poor souls who are deemed by the norms to need minimal care.



At Vikov, after a short chat with the Director we had to go to listen to a concert in the hall.

Victor was singing his heart out and one of the male sanitary staff had a voice worthy of a national talent contest. The hall was full of residents, most of whom were really enjoying the concert.

Loshe had to get in on the act as always!



It was obvious that the atmosphere at Vikov has already changed. The Director had tried a system of incentives so that people were awarded stars for good or kind behaviour and some of them had had an outing as a final reward. Lynne looked a bit dubious about this, but at least the Director is trying to give people something to think about and look forward to.

We talked about the psychologist post and what she had in mind. Initially she would just want the psychologists to work with 20 to 30 people. I think Natallia is thinking that the psychologist can help these people to improve themselves and their behaviour, whereas we were thinking more along the lines of finding out who the environment around them could be improved to make people's lives better. As Brian's report mentioned she had two possible people in mind, neither of whom sounded particularly suitable. We have asked Galina Femenok to see if she can think of any suitable candidates and Natasha from Mayflower will interview the candidates with the Director and our Natasha. She

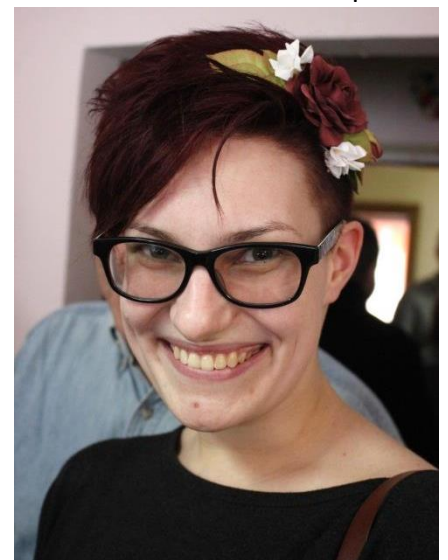


should also be able to help them come up with a suitable job description.

As we were going round and I was taking pictures of people this old man asked when he could have the print. I said 'sleydeshe ras' and he said 'next time, next time'. It turned out that he speaks quite a lot of English and he had a note book full of equations. He must have been a lecturer or an engineer and he either had some sort of breakdown, or started to develop dementia, and was moved to Vikov. Lynne has a

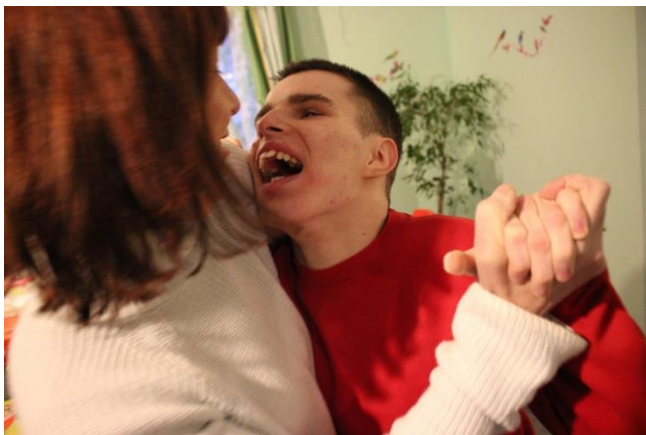
friend who will come in the summer who works with people with dementia and we hope she can do some training.

In the craft room they were making some beautiful hair bands and slides and Anya was genuinely delighted with this gift!



We had two visits to **Rodni Kut** which were very positive and happy.

Sergei was cheerful and friendly – Brian and Lynne have not always seen him like that – and when we talked to him about paying the salaries through Rogachev Association he readily agreed. I broached the subject quite carefully, but it seemed that he had heard about it from the Association anyway and said it was no problem.



Valentina and Zinaida from the Association came round on the Saturday afternoon to talk about the payment and also about the Assn. They had been offered a flat to use but needed to do quite a lot of repairs to make it suitable and there were going to be high charges for services. So it was decided that they would use Rodni Kut for all their craft classes and maybe on other occasions. They don't need office space there as the accountant works from home.

Sveta, who comes to teach the young people for a few hours a week, gave Stas a massage on Saturday afternoon and some sort of head massage for Nazar which seems to be very calming.



Nazar was very happy to share his talking photo book with his visitors. I don't think Sergei and the carers use it with him.



Anton loves to play in water but he was being given jobs to do –fishing things from the bottom of the bowl – which seemed to be spoiling all the fun!



We visited Privalov, Deputy Governor of Gomel Region, who was accompanied by Shutko, the Head of Social Protection and Zhanna, Deputy Director of Education (her boss Poroshin was at a Seminar in Minsk). We talked about the UNICEF project and then about a visit to Britain for Privalov, Shutko and Poroshin in May. He was enthusiastic about this and we decided on the most suitable date.

Then I mentioned that UNICEF would like us to take representatives of the ministries on the same visit. What did he think about that? He said he could not comment and then proceeded to comment quite strongly that it would change the whole character of the visit, the Ministry people would take over and they would be telling UNICEF that the project should take place in Minsk. I said that the Project could not be changed once the agreement was signed, and he said 'Don't you believe it! The Ministries can be very persuasive.'

I told him that the visit would be better funded if they all went together and they would stay in posher hotels and eat better food. He said he was not bothered by that, and Lynne later told him not to forget that he would be sleeping in a tent!

There may have been an element of him wanting to be top dog on the visit, but as I already totally agreed that the group would be too big, and that the chance for the Gomel three to gel as a team would be lost, I have written to UNICEF to say that, after consulting colleagues we have decided that the Ministry visit must be separate and later in the year. They will fund the Ministry visit, and I am hoping they will contribute towards the Privalov visit, but I'm not sure about that yet.

At Rechitsa Boarding School Victor was on his best behaviour. He told us that about 20 -25 children would be allowed to go to Ptich in the summer and he was very happy for volunteers to come to work with the remaining children and young people.

Lilia, who had interpreted for the group in the summer and Victor said she was welcome to visit any time she wanted to if she got in touch.

(I did not try to talk to Lilia about Sergei and Ira. She was only with us for an hour and then we dropped her back at



college. It would just not have been possible to talk about anything so sensitive. And on reflection I had thought that if Barbara had managed to host both girls for a fortnight and not discuss Sergei with Lilia, when she was dying to do just that, then I really did not have the right to. Brian fully agreed with this)

I nagged Victor again about Alessia's wheelchair which has been too small for her for the last two years. He said she does not want a new one, and the problem is that she does not want to lose the small light one for dancing, which she loves. If she can get a promise from him that she will be able to keep it for that, then she would be very happy to have a bigger one, which social protection can provide.



The carer for this little girl was delighted that after three years at Rechitsa, she had just started to walk.

Victor mentioned just before we left that he has a Scientific Commission coming to visit him from Minsk shortly, who are the body which would advise about changing norms.

His institution, while remaining for children and adults, is changing to a Psychoneurological Home, which means less staff and lower categories of staff. So a very positive sign that the possibility of changing the norms is in the air.

Next stop was **Babitchi Orphanage** on the long and snowy drive to Ptich Sanatorium.



The Director took us straight a room where all the tables were covered with handmade cards, well over 100 of them. They were beautiful and every one was different. He brought the kids in to be photographed with them and they all held a card they had personally made. I think quite a few had been made by teachers but we will stick to saying they are made by kids. I will print a picture of the children and a few words about the orphanage on stickers and then we can put it on the back of each card. If we decide we want to have lots more of these, then perhaps we could get the cards printed first and pass them on to the school. With the money I gave them in November and what we added this time we have paid about \$2 for each card. I am sure we can sell them for an average of £2.50, and it would need to be £3 or £3.50 if they are posted out.



Kapatkevichi Boarding Home is just across the fields from Ptich Sanatorium. This place is not psychoneurological, so is for people who are deemed to be capable. The Director seemed very pleasant and cares about her residents.



Maxim and Liza had been moved from Duyanovka to Kapatkevichi just a few weeks earlier. Maxim said everything was fine, but we know he has told friends in Gomel that he is not happy there. I asked if he would like to come and stay at Klimovka for a visit and he said maybe when the weather is better. He wants to be at Kapatkevichi to look after Lisa though he says the sanitary staff are not bad.

Lynne was delighted to see Youlia. She moved from Rehchitsa about a year ago. Sammi started raising money to buy her a wheelchair and then we were told that she would be made a special chair by the state. It was not highly adapted but she looked quite cosy in it and seemed happy.





Lilia moved to Kapatkevichi from Vasilovka six years ago. I remember that she was very depressed when she left Rechitsa Boarding School. She really wanted to go to college and there was nowhere accessible for her. So it was great to see that she was very happy at Kapatkevichi. She helps other young people with their laptops and smartphones and the Director said she is always busy with something.

It was a shock to meet this young man. He fell off a roof ten years ago and broke his spine, so here he is stuck in an institution. His English was good, and his French better. It is awful that he is living there. In an adapted flat he would live perfectly easy on his own, and he should be working. We had so little time, we will ask Natasha to talk to the Director to find out more about him and see if there is a way we can help him.



When we got to **Ptich Sanatorium** we talked with Pavel about some people from Kapatkevichi coming to stay for the day. As they are so close there seemed no point in staying overnight, although we might do that for Youlia and Liza as they are more disabled than the others. He was very happy to have day visitors. The cost this year will be 35 roubles per 24 hours and 25 roubles, including transport, if people do not stay. They will still be entitled to massages and other medical procedures.



That works out at £13 a day for residents so and 11 day holiday would cost £140. We could give groups of five or six people from Kapatkevichi half a dozen day visits and perhaps spend £1,000 on this.

This is the building which is most adapted for young people with disabilities. Klimovka group stay here, Rodni Kut and mums and children from Mayflower or Hospice. It is

really nice and Pavel is proud of it. He was delighted when Lynne said that now Ptich has been improved so much it is better than Nadezhda! We fixed the dates for the summer and discussed a few issues. Pavel is easy to negotiate with and last year he patiently waited a long time for payment for the holiday when our cash transfer went missing.

We finished a very busy and positive week with a second visit to Rodni Kut, a meal with Galina Femenok, who will be a consultant on the UNICEF project, and a train ride to Minsk.