

CHERNOBYL CHILDREN'S PROJECT (UK)

ПОДДЕРЖКА ДЕТЯМ БЕЛАРУСИ

Visit to Belarus November 2018

I flew on Lufhansa, arriving in Minsk just before 1am, so spent the first night in a Minsk Hotel. The next morning I visited Children in Trouble and Evgeny took me to The



Children's Cancer Hospital at Barovliani Hospital, He told me that the small houses, which it had been his project to create, are all full and always popular.

Tanya has just finished her treatment and should be ready for a holiday next summer. The wheelchair is only temporary.

We visited the Day Centre where children who live nearby are able to come in daily, and take part in crafts and games when they are

not being treated. This is Sousha with her mum in the Day Centre.



This poor boy has a sarcoma on his leg, and is also HIV Positive. This lovely girl with her mum were introduced to me as a potential for a holiday in 2020 and then I was asked if it was possible to do an operation on her hip as it was too difficult to do in Belarus. It was heart breaking to have to say No, there was no chance of that.



This young man came to Endon this summer, and was in for some routine procedure, so no need to worry about him!



This baby is one of two children who have a rare form of Leukaemia. They need 3 vials every two months of a drug which costs about £200 a vial. The total cost of treatment for both of them is \$10,000 and they cannot have a bone marrow transplant until they have completed these courses of treatment.



At the **Belarusian Children's Hospice** Anna told me about the 3 day conference she had organised the previous week, with EU and Swiss Funding. There had been participants from 11 countries, and Natasha and some of our Hospice Team had taken part.

In her office I met a woman from Israel who had come to give further training as a follow up to the conference, in *Bodydynamics*. (*Bodydynamic* is a precise and practical approach to working with the body to make verbal psychotherapy more efficient and effective.) I also met the Head of Open Society in Tajikistan. This is an organisation funded by George Soros, which helps to develop civil society, and one of their major projects is in palliative care.

Anna has applied for a grant to develop palliative care for young adults and she would also like to work with some of the young adults at Barovliani..

In Gomel my first visit was to the **Mayflower Centre**.



There were six young people in the Centre, with three of them due to stay overnight. Natasha says they usually average seven people with four staying for four nights. Social taxis have now changed their rules, so that a family can order a social taxi just once a week. This means they can come by taxi but then either Mayflower or the parents must find another way to get them home.



Natasha had recently organised a conference for Belapdi on Social Enterprises. She is hoping for a grant to set up a small social enterprise for the young people in the Robinson's Group.



Natasha and Tanya, the nurse, are both working on the Unicef project. They could not be more suitable or more qualified to do this, but I do worry about how much time Natasha has.

Tanya was very enthusiastic about Geoff's training and said it was great to hear about an idea or a way of working and then do an exercise to show why it makes total sense.

The Unicef project started with 377 families with a disabled child being interviewed. From this information each group chose 15 families to support. They have all chosen a wide variety of families – a single mother, a foster parent, a mother who has given a child to an institution because of her health, a palliative child, and children with a variety of disabilities from babies to teenagers.



I spent the rest of the morning at an SCT organised seminar at Zhivitsa Rehabilitation Centre, on the importance of physiotherapy for palliative and very disabled children. This was part of a project for which they had received a grant from the Hospice in Minsk.

Anya and I went to Vasilovka Boarding Home to see Sasha. I took him some photos from his

holiday in the UK in the summer. We had a good chat and Sasha was in philosophical mood, wanting to discuss many of the World's problems and how they needed to be resolved. He gets all his news from Russian TV so of course has quite a biased viewpoint on many issues, but he is bright enough to understand this and laugh about it.



Our next visit was to **Family Home 2000 at Klimovka**. Maxim used to be a frequent visitor when he lived at nearby Duyanovka. He now lives at Kapatkevichi, near to Ptich Sanatorium, but was having a month's holiday at Klimovka. He was really keen to see Sasha and Larissa promised that he would soon come to stay for a few nights.

Another young woman was staying at Klimovka for a few weeks. Natasha used to be at Rechitsa and then moved to Duyanovka at 18. She continued to have holidays in Italy, like many other ex Rechitsa people. Now that Duyanovka has been turned into a psycho-neurological institution she can no longer live there. She was going to be sent somewhere else, but a family in Italy have now said they will adopt her (apparently in Italy you can adopt an adult). She is very happy and will be going to live in Italy in January if all goes well with the paperwork.



Liena had recently been in hospital for one of her regular treatments. She has a lovely time there, getting on so well with the doctors and other patients. She has been going to the same hospital at least once a year, for about ten days I think, for the last fifteen years. Her health is quite good at the moment and her hearing aid was working well which makes such a difference to her being able to join in the conversation. She gave a lovely and very moving toast for my birthday.



Much of the talk was about Marina and Masha. They had stayed at Klimovka for a while after Masha was born and Greeshia and Ira in particular had loved having a baby in the house.

Marina now has her own Social Flat and Larissa was quite critical of the way she is managing her money. She and Marina have rather fallen out as Marina is fed up with getting too much advice from Larissa!

But Natasha thinks that Marina is doing fine. She visits her often to check that all is OK and tries to

avoid giving advice.

We visited Marina and Masha at the weekend, and then popped back with a Hospice nurse when she had some concerns about Masha's tummy. She is very lucky to have



the support of the Hospice team for her beautiful, healthy little girl! Marina

seems to be a relaxed and happy mum and she has made some friends in her block of flats. The social flat she has been given is wonderful. She has a big living room, a generous bedroom and a decent kitchen and

she is coping really well.



At **School No 5** the minibus was being repaired, but Aleg hoped it would be on the road again by the next day. The staff had painted a large part of the school during the summer, despite having zero budget money to do this. Aleg was actually taken to court and given 2 small fines for not doing certain repairs!



The wheelchair group were not in, because of the minibus, but we visited some of the classes working with autistic children. And we met this little girl, Angelina, who has almost no eyesight. One eye is completely blind

and she had an operation on the other which did not help, and her mother has been told that she cannot have another operation until she is 11. She is a delightful child and enjoys school but has to hold things within a few centimetres of her eye to see them.



I asked Aleg if he would like some volunteers at the school in the summer. During the early part of the holiday they have many of the children at school for a Summer Club and they need to do some more decoration. I said that we had a company who were interested in sending some student volunteers for a week who could work half the day on the decoration and half the day playing with the kids. These are friends of Denis's and he and Ira will bring them to Belarus in March to look at the cultural part of the trip and they could also visit School No 5. They could raise a little money for materials too, so Aleg would be very happy to have them.



The school had taken part in a competition to present pieces of drama about the environment and had come second with their play about waste being dumped in the Arctic amongst the bears; a TV crew reporting on it; and then a team of people coming to clear it up. They were very happy to get dressed up and perform it for us.



At **Terukha** we met the two young women who the Director thinks could manage to live independently in the future if they have the right help to prepare them. I said that they could come to visit Klimovka and see how they get on, and then it might be possible for one or both of them to come to stay for a while.



Shutko, Social Protection Director, had asked if we would like to help prepare another Klimovka type home near to Terukha. There are two houses nearby and they just need some

renovation to make them suitable, and the Director says her staff could work there. So it is a great plan, but I explained that Klimovka and Rodni Kut were models which we hoped would be followed by the State and we could not afford to create another.

Youlia, the Terukha Director is a neurologist by training, very bright, caring, and outspoken about problems. She is working on a project with Grodno Medical Institute to do a full assessment of the needs of all her residents and plans to do all she can to improve their lives.

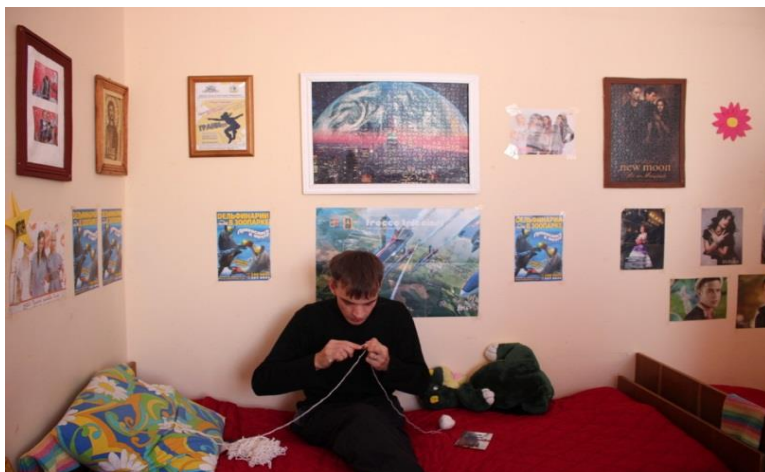


Our next visit was to **Zhuravichi Dom Internat** We had already met Shutko, the Director of Social Protection, and he told us that from January 1st the norms would be changed in adult institutions so that those with most disabilities and needs would have more staff to look after them.

Natalia confirmed that she would be getting another 20 staff (if she can find them in the villages nearby!) And she had already divided the most disabled group into two groups of 7 or 8 so that the carer can give them more attention.



Many of the bedrooms were decorated with either paintings on the walls or with pictures and posters, like any teenage bedroom, which was great to see.



We had our usual visit to the Craft rooms. It is not surprising that Natalia always wants to show off the work the young people do. If you enlarge this you will see how beautiful and intricate this work is. The young man who produced these did not want to pose for a picture.

Unlike Genna who always demands photos.



Here he is with the picture I took last time.

Petya was very excited that he had met his sister when he had been part of a group from Zhuravichi visiting Rechitsa for a concert. He told Natasha about it, using his communication book. We will have to try to organise another visit for him there, or perhaps help his sister to come to Zhuravichi.

Kristina is always delighted to see visitors and have her picture taken, this time with Anya.



At **Vikov** we talked with the Director about the work of the psychologist and teacher we fund. At first they had not worked well together but now were co-operating to organise activities for the residents. We went to watch the activities in the room where Ludmilla works and they were being greatly enjoyed by lots of people who would otherwise be doing nothing



We had a very happy visit to **Rodni Kut** where Sveta was making Christmas Decorations with the young people. Sergei was cheerful and positive about everything and they showed us lots of pictures of recent outings and activities. Valentina and Zinaida from the Association were there and they were delighted that I was able to pass on to them a gift from an inspector of the Health Prom / Hospice project. They will use it to pay the rent for a while on the small flat they have now as an office.

We finished our day in Rogachev with a visit to **Galina Femenok**, who is now head of the local team for the Unicef project. Galina has great experience so she is a tremendous asset to this project. She has been working on the Health Prom project for the last three years, aimed at helping families with children with disabilities to understand their rights, and that has just come to an end in time for her to focus on the new project. She will be coming to Britain with the group next week on a Unicef funded educational visit.



At **Rechitsa Boarding Home** the children and young people were practising for a Christmas Concert.





They were delighted with the calendars which feature Rechisa quite heavily this year. This little girl kept saying 'It's me! It's me!' And you can see how they love to get photos from this scrum around Anya.



They produce some stunning craft work. It was hard to believe these flowers were not real.

Victor is very much hoping that we will be able to bring volunteers to spend time with the young people next summer. The children will be going to the sanatorium again, despite rumours we had heard to the contrary.

We visited **Dom Dominic**, the home in Rechitsa which was set up a few years after Klimovka by an Irish Charity. It is now run by the local authority.

There are currently six young people living there but Luba and Victor are soon moving out into their own flat.





All the young people are capable of living independently, and Aleg on the left already has his own flat. He is also the Head of the local Association for people with disabilities.

When Luba and Victor move, the plan is to use their room to provide some respite care and some development of independence skills for local young

people who live with their families.

This young man is teaching himself to be an expert in a special type of draughts which is popular in Belarus. It looked completely unfathomable to me!

Our final visit was to meet the **Rechitsa Unicef Team**. They are a lovely group of women and Geoff was very impressed with them during the training. When I asked them about the training they were buzzing with enthusiasm and said they had never been to anything like it. They have started the assessment of their families and are looking forward to Elena's visit to the UK and hoping she will come back with new ideas and skills.

We had a wonderful evening meal with **Zhanna, Deputy Head of Education, and Tatiana, Chief Paediatrician**.



They are friends, and work easily together, and both of them are wonderfully supportive of all our projects. Tatiana took part in the whole of Geoff's training and is offering to do the paperwork on palliative care to help out our doctor Irina. Zhanna is very supportive of our plans for a new fostering project.

Natasha and I had a lovely meeting with some of the mothers and psychologists who have been

involved in the **Mental Health Project**.

We received a grant last year from the BEARR trust for a project to work with children who are in danger of being referred to the psychiatric hospital, and try to support them in the community. It

was only a six month project so when it finished we used some funds from the True and fair Foundation to continue it at a slightly lower level for another six months.

The mothers could not have been more enthusiastic about the support they received.

One mum has an 8 year old called Sasha who was thought to be hyper active, had no friends and school could not cope with him. He has calmed down considerably and is making friendships and people are saying they hardly recognise him as the same child. The second mother has a 12 year old who was wetting the bed and suffering from anxiety. The programme has solved his enuresis and massively improved his confidence.



The third mum is guardian to a boy of 12 who has been with her since he was six. They wanted to adopt him but he doesn't want to be adopted and wants to know about his birth family. He suffers from lack of trust, anxiety and being slightly hyper active. Being in this project has helped him so much he recently said 'Thank you mother for bringing me to meet people who could give me so much help'.

And the final mother has an 8 year old who is autistic. He is non verbal but bright and is now included in a mainstream school with a tutor. His ability to interact with the world has greatly improved during this last year.

The psychologists are Liena, who has worked for several years in our Hospice Team; another Liena who works at the Regional Diagnostic Centre and Nella, who is the Chief Psychologist for the Region, and is based at the Psychiatric Hospital. Earlier they also had a psychiatrist working on the project.

They worked in groups: children, teenagers and mothers; individually and with families. Body therapy was mentioned by all the mums as something which really helped their child.

They were desperate for the work to continue. I explained that we have a lot of projects and commitments, and limited funds, but agreed to extend till the end of the year so that meetings could be organised with educational staff to improve the attitude in mainstream schools to children with autism, ADHD or emotional and behavioural problems.

At the beginning of this project a Child Psychiatrist and Clinical Nurse Specialist in ADHD went to Belarus to do some training. One of the psychologists said that she thought she knew a lot as she has worked in this field for many years but what she heard in their training was like a revolution in her brain.

I said that I thought we could bring them to Gomel again next spring to give further training for professionals and parents and everyone was very enthusiastic about this.

At the **Psychiatric Hospital** we had a very positive discussion in the Children's Department.

Most children from families now visit the day Unit, with few staying in the 40 bed inpatient unit. But this is still generally full of children from institutions and, sadly, foster families.

We were told that very few autistic children stay now, which is great.

Natasha Begliuk, the Chief Paediatric Psychiatrist for the region, is visiting schools and institutions to advise about coping with suicidal tendencies, and to discourage unnecessarily putting children in hospital.

The hospital is now making more effort to pass all the relevant information about the treatment they have given, and any ongoing advice, to the parents and schools.

If any kind of abuse is suspected, hospital staff talk to teachers, social services and then the police. And continue to work with the child. This seems obvious but is quite new. When I asked about 5 years ago in the Republican Psychiatric Hospital in Minsk what they did if they suspected abuse, I was told that if abuse was reported they told the police, but if not directly reported, they did nothing.

We had a pleasant chat with Alexander Tsitko the Director of the Hospital but it seems that far less progress has been made with adult psychiatric care.

We finished with a very frustrating discussion about autism and schizophrenia. I asked if children's diagnosis of autism was still changed when they reached 18. At first he seemed to be saying No, but then it became clear that in Belarus the condition is called Children's Autism, and you cannot have it as an adult! So at 18 the diagnosis must be changed. It might be changed to just learning disability, or some sort of syndrome, but in many cases it is changed to schizophrenia. He claimed that this is in line with most of the world, and is very unlikely to change in the foreseeable future.



Irina was on holiday so I visited **Hospice Families** with Natasha and Tanya, one of the nurses.

Tanya was able to change this boy's tracheostomy to feel much more comfortable and show the mum how to do it in the future. He lives in a village in Dobrush Region a long way from Gomel and it is very worrying for his mum when his ventilator stops working, as it did a few days ago. He is able to manage without it for a while and a local electrician had been able to fix it.

This poor little chap lay in bed breathing heavily and he relies on an oxygen concentrator and other equipment. I wondered whether he ever got any happiness out of life. Then his mum picked him up and showed how wrong I was! Every time she spoke, he broke out into a wide and happy grin!

Linda Walker

