

## Ukraine: a population with a burn-out

23 years ago, Liliane Bollaerts from Edegem started an operation from her parish for people in the Ukraine. A few years ago she arranged a transfer to Leuven for a girl with spina bifida for a complicated back correction. Child-Help hardly ever arranges these individual transfers as we want to improve the situation in the country itself and do not want to invest our funds in just one child. However such a back operation is very complicated and sometimes vital.



Pierre Mertens on mission in a country at war

There was also a mother in Sudan who contacted us for a similar, but for her child also lifesaving surgery. I tried to send a surgical team to Khartoum to operate on the child there and to educate local doctors. However it didn't work out as these back operations are so complicated and also because complications can be expected after the operation. They cannot be dealt with locally. Also the material needed to perform the same surgery on other children is just not affordable in developing countries. We couldn't help this mother. Liliane did manage to help although it was not easy. However the operation was successful, the child is doing well. In the meantime the mother lives with her family in Belgium.

This is good for this specific family but doesn't offer a solution for the children in Ukraine. Liliane realizes this and therefore now wants to set up something for children with spina bifida in the country itself.

Three to four times a year, together with eighty volunteers, she sends 15 tons of medical material, clothes, toys, crockery and lots more to the Ukraine. Her work is also focused on palliative care and wound care. A combination that automatically got established through circumstances and opportunities.

This is typical for what is here called disdainfully the "fourth pillar". Belgians travel to Africa and meet a sympathetic man who works incredibly hard for a small local school that is housed in a kind of big carton box. Touched by his input and by the difference between North and South, these people of good will start working for a renovation of the box and later even for a real building with a waterproof roof. Great isn't it.

Initiatives that also a lot of migrants start in the countries where they originally come from. Apparently more money is transferred from Belgium to developing countries by migrants living here than via the whole official development aid.

There is nothing wrong with this, to the contrary, often this is much more efficient than streamlined NGOs which disturb the African countryside with their 4x4s. Of course these organically grown initiatives also get frustrated when they see that money is kept back or that donations are not well looked after. However these teething problems don't outweigh the high costs of NGOs with expats whose children go to unaffordable international schools and who sometimes cut corners.

In the meantime I have learned that where it concerns spina bifida or hydrocephaly, I have to accept with both hands the slightest sign of interest for our target audience as an opportunity. An important person in the network of Liliane is Ihor Vitenko. He is a Ukrainian doctor who, as his diploma is not recognized in Belgium, now works as a nurse. His story in itself is worth a book on its own. As a young doctor he wanted to work in the Crimea but was sent to Tchernobyl.

When he came back the public treasury was empty and he had to work without salary for six months. He left for Belgium with his wife and kids. It took 11 years to finalize his regularization, besides this he had to start studying all over again. He chose nursing and specialized in wound care. Here he also encountered a lot of opposition. Getting marks that meant he failed, by teachers who for political reasons didn't want migrants entering their sector. Then appeal and obtain a mark of 22 out of 25. He knows what it is to survive. Now he wants to give something back to his country. The public treasury succumbs to the ongoing war and a new invasion by Russia remains a realistic threat. Doctors in the Ukraine earn between 100 and 150 euros a month. With pensions of 35 euros a month the elderly population is starving. The conditions in Ukraine are no longer sustainable.



Liliane Bolaerts and Ihor Vitenko

This former Eastern bloc country so badly wants to turn the page on a heavy and dark chapter and saw a new change in Europe. The arrogant Russian occupation of the Crimea, the continuing fighting on the eastern border puts the internal politics under a lot of pressure... A country in crisis that is dreaming of recovery and via Liliane and Ihor knocks on our door for the group of people we work for. I also said yes because where there is war, children with a disability suffer probably even more.

Is there a connection between palliative care, wound care and spina bifida? Maybe there is.

The type of doctors that work on these subjects have a lot in common. What do you do when you cannot be cured? What do you do when because of failure of the system your child survives, blind with a head circumference of over 90 centimeters? Most doctors will walk away. They cannot help and look the other way powerless. However our "good" doctors don't walk away. Neither from the chronic suffering,

nor from the dying. This is the same case with the complicated wound care. This is often a long process of trying and failing, of getting up and falling down, from not giving up and from continuing the fight against infections, causes and effects... It is more complicated than surgery, maybe that is why a Ukrainian doctor here found a niche as a top nurse in a way that he can also make a difference in Belgium.

The end of communism wasn't a straight forward progress for our target audience.

Some years after the fall of communism in Bulgaria I had an art exhibition in beautiful Plovdiv: "The image of reality". I was then at the height of my artistic career. Bulgarian Airlines sponsored our flights. We were told to pick up our tickets at the check in gate, but when we got there, the tickets were not there and nobody from Bulgarian Airlines could help us. We saw our plane leave and after waiting for hours got the news that we could leave for "free" two days later at the same time. As I wanted to work on the scene I lost two vital production days.

During this foreign trip I took the opportunity to make contacts for our target audience and that's why I had organized a workshop on spina bifida and hydrocephaly a day after the opening.

I had worked really hard to be able to show something sensible at the exhibition and on the last day I went to the workshop on spina bifida with doctors and policy makers. Pediatrician Pedova came up to me after the meeting and asked me if I couldn't visit her hospital. This was just about possible on the day of our departure on our way to Sofia from where our flight was leaving. There were tens of children with spina bifida and hydrocephaly in a small room in the hospital. From the heads of the children I could see when the communist state medicine had been replaced by private and money driven medicine. The fall of communism also meant the end of treatment and shunting. Children older than 4 years had been shunted; if they were younger they were lying there, although well looked after, with growing heads, waiting for something that would probably never come.



After the fall of communism children didn't receive treatment anymore

This experience was an overturning moment in my life. In one and the same week I had been confronted with a situation in which I had produced “my art” under great pressure and with the need of so many children for which I had only had time right at the end of my trip.

This feeling was strengthened at the airport where we were sitting in a waiting room with Belgians returning on a cheap Bulgarian Airlines flight from some sex resort in an Asian developing country. While I still had the images of those dying children in front of me, their boastful tales of orgies couldn't have come at a worse moment. The world turns around money, but especially about not having money.

That week confronted me with the balance between two choices in my life.

Because of Plovdiv, spina bifida came in the first place and my art became a necessary accomplice.

Liliane, Ihor and Luba, the mother of the girl that was operated on, came to visit me on a Sunday morning between two missions. Ihor has all the contacts and explains that a big reform is taking place in Ukraine. Where until now institutions were reimbursed to organize services, the services will now be reimbursed and not the institutions. A more result oriented way of financing. There will be a health insurance and the patient can choose where he goes. The government adopts a more patient orientated attitude. Because of this a lot of institutions will lose their subsidies and they sometimes will have to look for other destinations. The government is also decentralizing the healthcare in the country. A lot has to be organized now with local government money.

People lose their jobs, buildings are looking for new purposes. This seems to be the approach of Ihor. It is good personnel that he wants to use. He wants to visit these buildings with me and shows me the locations on his computer. He has good contacts with the local governments of his region and sells this all as an opportunity.

Maybe now that Ukraine is opening up to change, this is the momentum to do something for our target audience, something that we were not able to do before. On the other hand, I am somewhat afraid to use our children to prevent others from going under.

I don't think it is the right motivation. Personnel that has worked for years in an underpaid government institute is maybe not the best choice. It is like I would make a painting because I have a frame, instead of looking for a frame because I have made a painting. In the first option the painting and the frame will always rub. I receive the most relevant information about the situation of parents and children in Ukraine from Luba. She has experienced it all herself.



Rivne, a desolate city with humorless architecture

The programme that Ihor suggests is very full. And then I have also asked to visit an orphanage because I want to know if there are, like in China, so many children with a disability. I make it clear that for me this is an explorative mission. To see what is necessary and what is possible. I want to listen with open eyes and an open mind. In that way I cannot do any damage. Ihor suggests I fly from Eindhoven to Lublin where he will pick me up. During our holiday in Italy I hear that Liliane has decided to come along. It is five years since she was last in Ukraine and she has a lot to discuss with Ihor. The journey to Lublin is long. A five hour drive and waiting for three hours at the border between Poland and Ukraine.

Rivne is a desolate town. Communism, with all its well meant social programmes has left a very ugly environment. Concrete sculptures, flaking grey buildings, which are even more flawed by loud advertisements for supermarkets and petrol stations. Some weird looking people are walking around the hotel when we get there at 2.30 in the night. A fifty year old lady dances to the music of her phone. A confused, unkempt young man walks around aimlessly while smoking, two women sit on a sofa completely exhausted. The hotel looks like a bouncy castle made out of concrete. The door handle of the entrance door is a white hand with its thumb up and the other one with its thumb down. My room has been plastered into a cave like construction. I get into bed without charging phone or computer. Sleep, as our first appointment is at 8 in the morning. The breakfast room looks like a beer garden. The hotel looks like a meeting place for clandestine couples and contacts.

First we visit the people responsible for the town of Rivne and afterwards those for the province. In the corridors of these administrations hang, in a communist hero design, the victims of the Euro-Maidam protests. The Ukrainian government has not yet found another language for her heroes. Communism has effectively destroyed the whole original culture. After the Second World War they deported intellectuals to Siberia, burnt books and rewrote history. Who is 70 years old now has never known anything else but communism and later on war. In the office of the person responsible for the province, the logo of the European flag has been framed like a piece of art but the image has sadly fallen out of its frame.



The framed European flag

The highest placed person introduces herself and says that the most important health and social representatives are present here to show how important our visit is. She confirms Ihor's story about the future reforms. The patient will get a health insurance and with this everything will be paid. The national healthcare will be decentralized. As in many countries it is about more efficient management, closer to the population. However unfortunately the financing doesn't always end up with the local administration. Her explanation fits perfectly in the international trends and politics. Inclusion, dismantling of orphanages in favor of foster care, dismantling of hospital beds in favor of home care, getting rid of institutions etc.



The Ukrainian fallen in a Soviet like design

She continues: we want to show you everything, the good and the bad and at the end of the day we are open to your suggestions of cooperation. A smart construction, I think. They show us, we look and see if we want and can add something and then we talk again. I have insisted on having a translator and also on a meeting with parents. Ihor has taken care of everything. Two translators and an overloaded programme in which we are taken, under great time pressure, from one institution to another.



Montessori, speech therapy, massage and all for free

The first and most beautiful project that we visit is a rehabilitation center in kids' size and which weirdly looks like our hotel. A kind of fairy tale in relief. Painted in a colorful way, homely, active, with a lot of therapies and patients. In a small room of salt crystals, parents and children with breathing problems are watching a video. Montessori, speech therapy, baths and massages, electro stimulation, light therapy, they have it all and they would like even more innovative material from us. They don't treat spina bifida or hydrocephaly. Parents that live too far away can stay overnight with their children. And this is all free for the patient. The medical director has been working here for 20 years and has built this all up. Children between the age of 0 and 7 are welcome here, but they want, if we pay this, to extend this to older children and other target audiences.

Large parts of the building are not used anymore and are proposed as potential possibilities. Too much highly educated personnel, but without a new destination the majority will find itself on the streets tomorrow and this beautiful institution will have to close. I am impressed by so many beautiful things, so many intense and very child friendly things and all for free. I have never seen this with us. This is also communism. They even employ four pediatricians! All underpaid but still priceless for a country at war.

I think I can't apply my story of painting and frame here. This is a good institution where I happily would



In a room with salt crystals a family and children are watching a video

send our kids. But is this possible and at what price? The director looks somewhat absent or washed out. After 20 years his position is also in danger. Maybe I am outsider number whatever who wants to fulfill his plans in his institution. They have nurses, pediatricians and sleeping places. It would be perfectly feasible to organize a continence management camp here. With four pediatricians here one might even be able to develop the whole aftercare for our children. However a good cooperation with the hospital regarding surgery needs to be established.

In the meantime, Liliane works on her own contacts and projects. She has appointments, takes notes, walks from left to right. She fascinates me. So much energy and so much enthusiasm. Also her voice doesn't sound as hard as on that Sunday morning. She is only interested in projects that serve the most vulnerable in the society.

In the children's hospital a congress room has been booked where a neurosurgeon gives a somewhat general talk on spina bifida. The different kinds of spina bifida, some slides, no relevant information about the situation in this country. I ask which shunt they use and who pays for it. In Kiev an own team has developed a shunt which costs 130 euros. The parents have to pay these costs. When they can't pay, they cannot be helped and will be send home. I know that this means that also here there are a lot of children like Josua in Manila, who will develop a head as big as a basketball.



Speech therapy in the rehab center

A specialist in genetics gives numbers on incidence. In the much poorer north of the province, the prevalence would be much higher. Only 6 percent takes folic acid supplements and there is no food enrichment programme. Also because the slides are in Ukrainian with a different letter type than we use, I cannot understand the real incidence. I think I understood 1 to 2 in a 1000, but I am not sure.

I give a slightly adjusted talk which I also gave in Manila, tell what IF and Child-Help do and why worldwide so many children do not get the care they need. There are also two parents in the room, but they get a bit lost between all the doctors. As we have to stick to our strict time schedule I do not get time to talk to them separately. It is a real shame.

Elena is the mother of a boy who is a bit older and who has sight problems. She is one of the contacts of Ihor and Liliane. She contacted me as in anticipation of my visit, she wanted to establish a foundation for spina bifida. She is a driven lawyer. I already got her in touch with Janina in IF who also speaks Russian. They already held a skype meeting. Her son is 17 years old and does a lot of sports. He already participated in the Paralympic Games. She sees a spina bifida organization within her own foundation and as a step in her plan to establish a private rehabilitation center. I explain to her that a self-help group is not the same as a foundation which itself foresees care. Parents first have to get together, learn from each other and when they are strong enough, become a lobby group for the right for good care for their children. Don't organize care yourself as then you get conflicts of interest.

She immediately suggests to start a separate organization. I ask her not to do this but to support the Ukrainian parents to start something themselves.

The hospital itself could also start a continence programme and the coordinated after care is more evident here than in the rehabilitation center itself as in the hospital all medical disciplines are available.

We also visit an old peoples home in a former holiday camp for communist youngsters. A run down but beautiful location with a pool that has been empty for the past 20 years. It is a beautiful location for an exhibition of modern art. With a good plan and a lot of money everything is possible here. Also a rehabilitation center of which they can only dream here. Elena sees this as a potential place for top

sportsmen and women with a disability. And so everybody has his and her dreams but no money. When I dream with them, this would also be a good place for a continence management camp but a rehabilitation center would be more suitable.

My translator is a young woman who has done traineeships in several western European countries. In her opinion everything goes so slow in her country. She is irritated as according to her Ukrainians expect too much from other people and don't start things themselves. I hear Ihor say the same things.

They ask me what I think of Rivne? I think but what can I say after half a day? When I carefully try to say something, my translator intervenes and answers in my place: "Way too old-fashioned, still a communist



Translator with a distinct opinion

country, right?" and she looks at me like if she has answered what I didn't or couldn't say. I laugh and tell her that she is supposed to translate. Later in the day she says that people are tired. They had put their hopes on Europe but they don't see any improvement. Everybody is leaving the country and there is still the threat of an invasion by Russia. "Ukraine doesn't have any influence on her own future. The agenda is set internationally", she sighs. This is probably true. It seems like a country that is tired of fighting. Young people leave to go abroad and the rest of the population stays behind in a state of burn-out. Wouldn't you?

That is why projects like Liliane's gain in importance. It is probably also no coincidence that she has attention for spina bifida.

The orphanage that has been added to the already overloaded programme lies outside the city and seen from the outside looks like a beautiful green location with beautiful non-communist looking buildings. But also here I don't get to see any children. I ask a young psychologist if they have a lot of children here with a disability. Where first they told me it was 40%, she says 10% but no children with spina bifida or hydrocephaly. In China you have institutions with sometimes a 1000 children whom are almost all severely disabled. I have never been able to enter any of these institutions. Before I can really see something, we have to leave to meet the administrations. This is how we finish the day in Rivne.

I see several possibilities which I share with them:

1. Child-Help can donate shunts to Chhabra for parents who can't afford them.
2. A continence management – project and camp in the children rehabilitation center if they have faith in it.
3. Appoint a pediatrician who can start up the coordinated care in the children's hospital and if necessary pay him/her a top-up to do this.
4. A training course in continence management and coordinated interdisciplinary care by our Slovak partners
5. Material for a continence management programme
6. Supporting the start of a parent organization or self-help group.
7. In function of prevention, check what FFI has already done in the Ukraine.



Everywhere our delegation poses in front of the buildings

Nobody reacts to these suggestions. They don't even take notes. Maybe they are disappointed and were hoping for large sums of money which they could use for the rebuilding of the run down swimming pool. Maybe it is late in the day for them and they want to go home. We still have to drive two to three hours to Ternopil. Ihor was born there and our day starts with a visit to the children's hospital. The director and his assistant receive us in the meeting room. They give us some data: the hospital is responsible for the care of 200.000 children in the region. They have 15.000 patients per year and also run a policlinic. They organize mobile teams which go to local hospitals in the region. I receive a hard cover book about the history of the hospital. I ask for data on our target audience. They have 66 hydrocephaly patients of whom 25 have spina bifida.

Their protocol foresees in hospitalization twice a year for a follow up. In itself an interesting formula if they would bring the parents together at the same time. I want to ask questions but they are postponed to the meeting in the meeting room. About 30 parents some with and some without children are waiting for us. I adapt my talk and try to give them hope by introducing them to successful adults with spina bifida in our network.

Parents need belief and a long term perspective for their children. I tell them what a Ukrainian parents

association could mean and advocate for a continence management project. It becomes an animated and interactive discussion in which I depart from their questions and problems. I answer where I can but especially try and find solutions with them. Before answering I ask the other parents present for advice. One and a half hours is not long enough but once again the programme demands that this important meeting is interrupted. We have to go to the policy makers of Ternopil. The parents protest and I ask if the meeting cannot go ahead without me. But that is not possible. I can come back here in an hour and continue the discussion with the parents who can and will wait.

The meeting in Ternopil takes place in real Sovjet style although they probably do not want to hear that. Also here the change in power has had no influence on the imaging. A big oval shaped table full with



In Ternopil there is no continence management programme

plastic flowers separates us from the ten policy makers. They all say a few words. Photographers and a local television team capture everything for the evening news. Liliane explains how she works and what she has already achieved in different parts of the country. I add a few words. We get a pin in the colors of the city and Ihor gets a frame which thanks him for services offered.

Afterwards I am allowed to go back to the parents and we continue in a smaller group. The urologist is called in and he knows CIC and oxybutinine. He has two patients that use it. However most patients don't even know CIC, I asked them this in the morning. There are probably not enough patients here to start a real spina bifida team unless the programme rehabilitates the hidden and abandoned children. There must be survivors here too that do not receive any care or treatment. However the parents have been woken up and want to continue with this. They discuss how they can register as an organization. Most of them have never met before. The feeling of not being the only one really helps them. I write my email address on a piece of paper that gets photographed a lot. The rest of the day I have to look at refreshed or rundown buildings.



Everywhere our delegation poses in front of the buildings

Communism has had a chronic lack of humor which you can feel in their architecture. Between the desolate buildings of Ternopil there are several churches as the only visible opposition. In the city they can hardly fight against the Russian concrete but throughout the country they are sparkling signs of change. You can hardly call it progress because it goes back to a past long gone. However it is a rehabilitation of their rich cultural past. Only the nature offers solace here. At the end of the day we go for a walk around a great lake formed by a dam. Ihor was born here, studied here and got his diploma here which is not valid with us. Even though the Ukraine had a good education system. His country has a lot of highly educated people for whom there is no work. For more than six years Ihor has not been able to come here and has not been able to visit his parents. When, after all these years he found himself back at his university at this lake, he cried like a child. Also when he tells me he has tears in his eyes.

The government pediatrician walks with us and asks me about my impressions. She complains about the lack of respect of some patients towards the underpaid doctors. I tell her that our parents have already gone through a lot with their children and with care givers and that their reaction often has an understandable cause. When you listen to them



In meetings with the government of Ternopil, with flag and all



Liliane or driven idealism

they become your most faithful patients. Once again I plea for a coordinating doctor who has authority on the basis of his/her knowledge and in a relationship of equality looks with them what is best for them. These parents need one point of reference. Somebody who takes them seriously.

Before we set off on our seven hour trip to Lublin, staff members and policy makers from Ternopil come to our hotel to make plans. No words but deeds. What is possible in Rivne, is also possible here, maybe even in a better way as the parents are more involved. I mention the same seven points but here they take notes, appoint two people responsible and Ihor, who will stay in Ternopil for another two weeks, will follow up.

Ukraine is a country in crisis with a population in a state of burn-out. A new generation doesn't want to wait anymore and leaves the country or wants to start something tangible now. I would love to contribute to this but leave the initiative with them.

Liliane keeps on intriguing me. She is like a bulldozer who goes straight for the goal but who can also deal with setbacks. By getting to know her better I learn that she has an impressive CV. She was a teacher at the KUL, the University of Leuven, where she taught social "agogiek", she has been president of several national and international organizations and has worked her whole life for minority groups. She talks like a train but never bluffs. She talks with happiness about how all this has happened to her.

A driver who looks somewhat like Mister Proper doesn't speak any of our languages. In sign language he tells us that this old government Mercedes with leather seats is his own property. With a photo of his wedding and a very long limousine he shows us that he has left poverty behind. In a petrol station he buys the three packets of cigarettes that are allowed for three people and distributes them over three places in his car. Two visible on the shelf, the others in hidden places. He sells the packets after the border control. You can become rich by working hard and using all opportunities. A lot of small things make something big.

During the long way back to Lublin, I enjoy Liliane's stories. I ask her why she chose the Ukraine. As a member of the parish team she was allowed to go to a talk by a bishop. He talked about the disgraceful state of affairs in the former Eastern block countries and the poverty there. She went to him and said: how does it help the people in those countries if we talk about it, we should do something. The bishop encouraged her. This is how it started and with a bunch of volunteers she started lots of initiatives in the Ukraine. She is proud of her 80 volunteers, none of whom get paid. To find new volunteers she approached people on the street. She started a project for street children in Lviv.



Nature offers comfort in this country ravaged by a war that is almost impossible to win

With a bus they drove to the poorest neighbourhoods and gave food and shelter. There was a doctor who could deal with the most urgent medical problems. Recently this bus has been confiscated by the army to transport soldiers to the Eastern front. She also supports a consultation office for abused women and a social patrol. In Chevongrad she has installed a soup kitchen for fifty old age pensioners and a cook, paid by them, has been cooking for nine years already for this group of penniless pensioners. In Brodi they have supported a shelter for former prisoners which combines professional education with spirituality. With Ihor she undertakes a project concerning wound care. In Kiev they have organized a colloquium on palliative care. And then there are the transports of goods. Impressive, isn't it! It is not a coincidence that Liliane, who cares about people who have fallen out of the boat socially, also cares for spina bifida. I only saw children who got surgery, all others I lost sight off but not Liliane. Neither she, nor the Ukraine were love at first sight. Now I love them both, the country and the woman who opened the door to us and to our children in the Ukraine.

