

HemoStories Interview in Guatemala (transcribed and translated into English):

Blue- Holly,
Black - Marisol,
Maroon- Faviola

Hello and welcome to another episode of the HemoStories podcast. I'm here in Guatemala City speaking with ...



My name is Marisol de Monteroso. I am the president of the Hemophilia Association in Guatemala.

Thank you for being with us. We would like to learn about what it is like to have hemophilia in Guatemala, What does that mean? How is it treated? What is your story? What can you tell us?

Sure, it's a pleasure. Having hemophilia in Guatemala is very difficult. The only ones who have "prophylactic treatment" (I say they with commas because they don't always have factor) are those with social security, which is 30% of the population with hemophilia.

Hemophiliacs suffer a lot. They often to have prophylaxis. They are treated when there is a real need, true emergencies. Also, even those with social security, who are treated and have that right, they often don't give the proper doses that are recommended by the world federation, but they give them much smaller doses, and the treatment is much longer, prolonged, and their time in the hospital is much longer. This makes it much more difficult to work or to go to school.

What about preventative treatments?

Preventative? Preventative treatments are not given in Guatemala, definitely not. Treatments are only given as needed in severe cases. And the only preventative treatments go to, as I mentioned, those on Social Security (30% of the population).

But the problem here is that they give the same to everyone. A severe condition logically requires a lot more than a mild one, but here they give 15 factors or 12 factors every 15 days, or 24 per month out of 250 units per vial. For an adult, this is insufficient, right? So, for the majority, you can see on our website, we have many cases in photos of the damages they suffer: matrosis, the teeth, they can't pull them out, so their teeth are in bad shape, and what we do it try to teach them how to take care of them, how to maintain them, oral hygiene is so important. But sometimes the people live very far away, and often they can't attend.

Yes, it is very serious, I can see. Earlier you said that people have died this year.

Yes, since 2010 until now, we have lost 24 patients. In the beginning, no one lived past 12 years of age. When I began attending meetings and trainings of the world federation, we began to implement the preventative care at home, right? Putting ice on injuries right away, going to the hospital. This has helped this generation reach adulthood. But, unfortunately, because of the economic shortage in our country, the corruption that we have, it has been even more difficult to get access to treatment and we have lost more than 20 patients.

Explain a little more about the corruption and what you are saying that the economic situation for those who don't know.

I'll give you an example. Someone donated a treatment center to us. The minister of health was in agreement to sign a contract to enable us to secure it, but in the last two years, we have gone through six ministers of health, just in two years. And imagine the amount of time each president lasts

They change.

They change. Usually this is because there are disagreements, or they are found to be doing things that are anomalies, which is the case now. There are prisoners from the president of the republic to high ministers and hospital directors, even including medics that help patients. So, all this has made things difficult for us. We couldn't get the contract signed because every time we were about to get it signed, the minister changed. Unfortunately, we lost the treatment center because it was paralyzed for four

years. They couldn't comply with what they had established. We never asked for a cent. We don't have any economic support of any kind and we didn't have any money to pay when rent payments had accumulated and such. In that case we had to undo things. People who had donated came so that everything would be legal. They saw everything we did and we had to let go of the center, sell everything inside, and pay off debts that had come from being in a place that wasn't ours.

Wow, horrible. Tell us a little about your story, your son, and your experience with hemophilia.

When my son was born, I didn't know what hemophilia was. I hadn't even thought of it because I had no history with it and no one ever talked about it. One time I was cutting a baby toenail, and I cut a little off and it started to bleed a little, and it didn't stop. We were a little scared because he was bleeding a lot and it wasn't stopping, so we had to take him to the hospital. There, they didn't diagnose him because they didn't have that ability at that time. When my son was three, he had a bleed in his brain. Since there wasn't even diagnostic ability in the whole country or anything, the doctor looked at him and said he was a hemophiliac, just by looking at him, and that he had to go to the United States so that they could properly diagnose him and treat him because they didn't have factor 8 in Guatemala. So, we had to emergency travel to the US where they diagnosed and treated him. When we returned, we knew he was a hemophiliac. All of the costs of the trip and the purchase of the factor and the cost of bringing it back, well imagine, it was so great that we had to sell a house to be able to pay for that emergency.

So, you knew he had hemophilia. What did you do? There wasn't an association or anything. What was your path?

Well, the the truth is that in those moments, one feels so alone, you know? And helpless. Because I had never heard of this. I didn't know who in our country who had it. I knew I had to start to learn how to bring factor into our country. And I had a feeling that I should start an association. I met a doctor who supported us a lot. And she worked with us to get it started. We worked during a period of 13 years with attorneys, paying for everything personally so they they would fight the law so that at least those with social security could get treated. That was the first purchase. That how the association began, taking from examples of other associations that we wrote to, who sent us statutes and such because we were - we didn't know anything, anything, anything!! It took two years to form, with statutes and everything, paying for everything ourselves. We achieved something established.

What do you think you have achieved since the beginning of your experience with hemophilia to know? I imagine that the situation has changed a lot here in Guatemala.

Look, the situation really hasn't changed much. Even though we have wanted to do so much, because just the treatment center that they had donated, prophylaxis, was marvelous. From not having anything, not knowing anything, now having factor, well they made the purchase and there was factor in Guatemala. The national hospitals like San Juan de Dios only buy it on demand, but we keep working and trusting in God that we will continue one.

Thank you. Now we have a doctor joining us. This is doctor:

Faviola Valbert.

Thank you for being here. She just got here. She is going to talk to us about how hemophilia is treated here.

Perfect, it's a pleasure. Well in Guatemala we have very little access to treatment for hemophilia. About 16% of the population has access to a social security. Another small percentage, less than 5% has access to an insurance that can cover this illness. The other 80% of the hemophilia population is unprotected. The health administration doesn't cover prophylaxis for this illness. They only give treatment on demand (emergencies), which in many cases is with cryoprecipitate, in some cases with factor or with plasma recombinant that they use. With donations, the government buys factor. If a child or patient comes to the hospital and needs it, the government will buy factor, but always in quantities that are less than they need, and only in cases of emergencies. Only treatments as needed.

Normally the patients don't receive the doses that is recommended per kilo that they weigh, nor the doses that they need for the pathology that they have. In the majority of the cases, they give two jars in the morning and two at night, and that is the standard treatment for all patients.

In the case of patients that have inhibitors, when they can, they buy treatment, Feiba or factor 7, but in the majority of occasions, where there is a serious complication, they give high doses of cryoprecipitate and transfuse a lot, along with steroids. If it goes well, perfect. There are patients with whom they are able to stop the bleed, but there are others who die because they don't have access to factor.

Devastating.

Okay. What does your association do? Do you have annual meetings? You try to educate people, but how and how often?

When we received enough donations, it was like a hook for people, so they were bringing their factor because we donated. It was obligatory to listed to the training first about how to cure yourself or rather how to treat yourself with first aid from home. We taught them about cleaning and how to do their dental care, oral hygiene is so important, the importance of putting ice on an injury right away, and the need to speak up about injuries they may have had but hid from people, and all of this to avoid them coming very sick to the hospital. We did this regularly every Friday, 4 times a month.

Mucho

But no one knew anything

How many people would come each time?

About 15 - 20 people. That was the day that people had appointments in the hospital, so we took advantage of this. Even the doctors gave the prescriptions to them, knowing that we had factor, so they would write the prescription, and we would take care of it. But now that we don't have the amount of factor donations, it is more difficult the get them to come, and they only come when they are in serious condition. Now we try to do it once a month, but sometimes we make the effort and no one comes, right? Because they don't have access to travel. They live very far away and they can't come because to pay for the voyage is very difficult, you know?

Yes. I can imagine how difficult it is.

Doctor, you work here in Guatemala, right? How many other people or hospitals are there that can treat people with hemophilia?

There are three hospitals in Guatemala that can treat people with hemophilia, officially: Hospital Rusbel, Hospital San Juan of God, and the Institute of Guatemalan Social Security. However, all those are in the capital city. Everything is in the city. There is no way to diagnose or treat outside of the the capital. Everything is centralized. If a patient has a lot of a lot of money, a private doctor and care for them in a private hospital. You can be attended in a private hospital, but this is rare. The majority are care for here in the three hospital that I mentioned before.

So, if you live far away...?

No. If you live far away, you have to come to the capital. There are many people who, when they see the illness and the seriousness of the illness, come to live in the capital. They come with all that that entails - leave their jobs, look for another job here, leave their homes, start renting here, start from scratch.

This is one of the big problems we have with the diagnostics. It can only happen in the capital city and they can't send the samples because they degrade. The samples in time... factor 8 gets consumed, so it isn't a valid sample. For example, there are many places here in Guatemala that are 8 hours in bus, 14 hours in bus, so when the sample arrives at the lab, it is no longer valid to quantify factor 8. So the patients have to travel, and many times when they are in a serious state in their village, they don't even make it, even to get diagnosed. They die, or if they make it to the capital, already in very serious condition, the diagnosis isn't able to happen.

This is a big problem. We lose a lot of patients. Often patients don't get diagnosed until they are 14-15 years old. They are old enough to have had to leave school during much of their illness, but nobody had ever known why or what was wrong. They never had access to a diagnosis and didn't know what to do, right? They just had to fight the pain and make efforts where they could. They have had hemorrhages without knowing that they were hemorrhages. This is the reality outside of the capital where the diagnostics happen a bit faster. It is very sad.

Yes, so sad.

I only have two years working with the association, and I've seen that the work that they do for their patients is very strong. If they see patients that don't have factor, they try to help them by looking for donations from patients that they know have access to factor, perhaps in excess. They move quickly to see in what ways they can help their patients. And from a psychological point of view, which is so important and very overlooked here, they support their patients. They nourish them, and when they are newly diagnosed, explaining to them how they need to take care of themselves. All of this part of the illness that deals with education they don't have in the hospitals. When they have a diagnosis - because these are 3rd tier hospitals - they are not specialized in hemophilia. They give a diagnosis and treatment, and the patient heads out the doors of the hospital without really knowing what they have or what it really means to have hemophilia.

And they feel alone.

They feel alone, exactly. So, the association welcomes them, they offer playful activities twice a year, or as often as they can. The children are happy. They eat breakfast together. I know it isn't the solution, but at that time they have a discussion, they give them something to eat, and they give them a day of what they are trying to do with the minister of health. Throughout the year, they do many meetings, and they do meeting with the minister of health. They attempts to make laws, they talk with this person and that person.

Guatemala is really an unstable place politically. The leaders change very frequently. The ministers change. As you have seen, even the president changes. It really isn't a stable government. And the politicians change. You get the sensation that you are not advancing. You have to redo things or re-explain projects, but we always have hope that the World Federation of Hemophilia is helping us and supporting us. At least we know that the patients we have with hemophilia can know what kind of hemophilia they have and what level of severity they have to be able to tell how they need to take care of themselves because it isn't the same for someone with a mild form as someone with a severe form. Many times, we know they have hemophilia, but we don't know how severe, so we can't guide them with their diagnosis. You can't scare the whole world, either. Later the patient might say, "Well, not everything is happening to me that they said would happen, so they must be lying. They are trying to scare me". Everything is based on a good diagnosis to be able to help the population, to be able to give them a good education and guide according to what each patient needs.

Now, the biggest goal that we have is to be able to to a census, to be able to go to all of the areas of Guatemala, to all of the rural areas and look for the children who are bleeding where no one ones, no one orients them. They bleed and if they bleed from their nose, we help them. If they have a problem in their knee, everyone helps them, but no one know what is wrong with the child, you know? There are children who suffer and suffer until they have to have an operation of appendicitis and they die in the operating room, or whatever reason they might have to operate, sometimes it is for parasites. And they die there in the operating rooms. So the idea is to go and diagnose these children. We probably won't be able to treat them all at that time, but we will have some equipment or numbers to show to the state that we aren't just 250 in number, but we are 1000, or 2000. This really is a problem and you have to turn and look at these patients. You can't abandon them or leave them to die without treatment.

Yes, of course. How many are there registered here?

In the association we have 247 registered patients.

And the population of Guatemala?

There are 17 million.

So, we know that there are....

More.

At a minimum, 1,600, right? Without taking into account von Willebrand, which would make it much more.

We don't have that. We don't have it, because it isn't diagnosed.

Yes, you have it here, but...

Yes. We don't know. Until recently we didn't even have a way to diagnose it. It's been about a year since the tests came to be able to diagnose it. And they are expensive. They are very expensive

And one has to pay for it oneself?

In a public hospital when they have the reagents, no. But because it is so expensive, they often don't have it. If they have it, they give it to everyone, even the patients who come with factor 9, who have hemophilia B, I've seen that they give it to everyone. I imagine it is because when they open the reagents, they have to run the tests, so they give it to everyone. Those who have hemophilia A, those who have hemophilia B, so that it doesn't go to waste.

What are the goals that you have as an association today?

Our short term goal is to conclude the study that we are doing of diagnostics. Have the resources to the the educational activities that we do annually. We have to work on that daily to be able to achieve getting the resources for these trainings.

Longer term, present the project of a national census.

Long term, be able to have therapeutic guides for Guatemala for treatment on demand as well as profilaxis, which we don't have. And achieve a political state to the point where they cover treatment for patients with hemophilia, and to be able to have integral treatment. To be able to have psychologists, to be able to have dentists who are specialists, to be able to have traumatologists who are specialized, because the

patients often go to just any traumatologist and the patients go in and tell them that they are 20 years old, and are told that they need a prosthetic knee, without even thinking about how expensive this can be, and that every 10 years you have to change it... it doesn't make sense. It doesn't make sense. They come in saying that they are going to be operated on. The doctors don't know the risks that they are taking with their patients. So, ...

Education

Yes, education. This is why it is so important to have specialized doctors and very specialized neurosurgeons, because children come in with cerebral hematomas, and the first thing the doctors want to do is drain them, without thinking about it first or putting them through other treatments first. So, the problem gets worse, right? We need unity.

How did you get involved in all of this?

How did I get involved? I came to Guatemala and I started working in the Cancer Institute. There was a was a hematologist who, sadly, passed away. I came to work in his place. That doctor supported the Hemophilia Association, so through him, they contacted me.

I studied in Barcelona, in the Vall D'Hebron Hospital and there was the union of hemophilia of Barcelona. We saw patients, all of the urgent hemophilia patients came to us and we did a rotation in hemophilia, so I was familiar with the illness, and I knew how it was treated.

When they started to explain to me how things were done in Guatemala, I fully committed myself because these are things that touch you. When I saw the children in Spain, how they ran, they came and went, and then when I saw the children here in Guatemala in wheelchairs, dragging their feet, I said no. You don't need anything more than that. You see the children, and you get involved.

You have to do it.

You have to do it, absolutely, yes.

Also, tell them that the Center brought us together.

Yes. There was a Center that come to be with the idea that the State would give the drugs, and you could contract specialized doctors. And the idea was that I would work in this Center. But really we weren't able to achieve this. There were always promises with the government. They would be at the point of signing something, but it never became a reality to have the integral center to manage.

The goal is to have another?

Yes, yes, absolutely. Our goal is to have a Center. Where the children don't... There comes a time when a child doesn't feel ill. They have a condition that you can treat, but they don't have the sensation of being sick. Because they go to third-level hospitals. That is where they have to go, alongside patients who are dying. While they are in a seat waiting, they can see someone dying off to the side. This is the life of these children.

What is a third-level hospital?

Third-level? They are hospitals that treat cancer, big things, serious things. Invalids, accidents, major surgeries, patients who are hooked up to tubes. So, the children grow up seeing people hooked up to tubes, because, unfortunately, in Guatemala... in other countries, a person hooked up to tubes is in an intensive care unit, but here no, you see them in the emergency hallway because there is no where else to put them. So, they put them in tubes and the keep them ventilated in the hallway.

So, all of this the children see. Or the adults, the youth. Because in Guatemala, until 12 years of age they treat you in pediatric hospitals. At 13, when you are still a child, you have to go to the adult hospital and see all of that. A visit to the hospital is to find yourself among a mountain of calamity. And they grow up like this, with this trauma of being sick and living with this illness.

In Guatemala, the hemophiliac children are also very malnourished. They associate it with the illness. They say it is because of the illness. But really, if they had proper treatment, the children wouldn't be that way. They would be able to do exercise, they would be able to develop their muscles, but they are all bones.

Yes, we see that in the United States, children can lead lives that are almost completely normal.

Exactly. Here you see the children, and... at the beginning, I had the idea that it would be like the children I saw in Spain. I wondered, why are the children here malnourished?

And they had told me that it was because of their illness. I thought, no, it's not because of your illness. But, later I understood that without factor, they can't be mobile.

One of the principle problems that we have with the patients because of the fact that they don't have factor is that they suffer from pain. Probably their main problem isn't even the serious hemorrhages, but ... I mean it isn't even the patient seeing that they are bleeding, but it is the pain that they suffer day in and day out. They wake up and already have hemophilic arthropathy. They have a lot of pain. They wake up with a lot of pain. To articulate how to move and start the day, start with pain, we don't have it. There isn't pain management. These patients don't have a center, a place to go. They don't have... they have external consultations for questions, normally for about 5-10 minutes during which there isn't proper pain management. For many of the patients for pain, the mothers give aspirin. They give anti-inflammatories or steroids which make them bleed more. In severe cases, they don't have access to morphine or access to effective pain management. So, we see that we don't have effective treatments for the patients, but we also don't have palliative treatments. So, really these are children who live a life of suffering. There are very painful features. Even if they are in an agreeable environment, often the simple act of moving one leg that has a bleed reminds them of the pain. I've never seen knees like the ones I see here in Guatemala or elbows like the ones I've seen here. This has to hurt. And it hurts every day. Really, pain is the thing they suffer from the most here in Guatemala, and it is the most sad - that they live their entire lives with pain.

[And how can they study or work like that?](#)

Of course, definitely, you can't have a life. They are not going to play. They don't have a mind to study. They can't work. Everything is difficult for them. There are patients that manage to get a job in their adult lives (because someone was kind to them) and are able get on social security, but there are people who are not able to fulfill their jobs. So, someone give them a job, but later they can't fulfill it.

We have a patient who is a nurse. He chose to study nursing, probably because of his own illness, but he can't do the work because he goes with crutches and when he has to do things, he does them with pain. He is receiving prophylactic treatment, but he already has a lot of joint issues in his knees and and ankles and he is wounded. Even though he receives factor, he always has pain. And he doesn't receive sufficient factor. So, he suffers. And he suffers psychologically. He says to me that people think he is lazy and doesn't want to do his work. So, he starts to work, and starts to work, but after a week he can't anymore because he is in bad shape with his joints.

We spoke about how an illness that you don't see. When you don't see it, it is difficult because people judge.

Yes, because for him, everything hurts, but he's "lazy" because no one sees it. Another part of it is dignity. He's not going to go around crying in front of everyone and saying that it hurts. It's complicated. To live a life of labor, if we don't take care of them when they are young, later when they are bigger and start working to be able to have the right to factor, their life is already destroyed. You can't rescue - it is difficult to rescue them when they are adults.

What hope do you see for these people? Is there hope?

The hope is that we can have unity in the way that we treat them. Where those who have this chronic condition, can have good pain management, good physical therapy that will improve their muscle strength, and attempt to introduce them to societies from a psychological point of view. From all points of view, including genetic, because here, there is no genetic counseling. There are many people who have a brother who is a hemophiliac, and they, the sisters - who have sons, sons with hemophilia. They are carriers and they have sons with hemophilia, so ... really, the system is failing, because they probably couldn't adequately inform these people. That patient continues to suffer. Suffering for their brothers, and now suffering in the flesh with their children. The truth is there is no effective control on this point of education, because if we don't have sufficient education for the patients, their sisters are even more forgotten in this world. The sisters don't attend the discussions. We would like to have those discussions. The thing is, how do you get the rural populations to come to the discussions? As Marisol has said, you get the people to come to the discussion when you have factor. They know that factor is very expensive, so they make the grand effort to come (borrow money...), but to borrow money just to come to a discussion, they don't see the value. So, there really isn't a way to bring them to the city.

Also, I wanted to add that, what happened to me when my son was 12 years old and had spent three weeks in the hospital and one outside, you know, there came a time when he had a hematoma and he said that it would be better if we let him die. You know? Because he felt that he was a heavy burden for us, including economically because we had been living on a tight budget to afford his medication. He's not the only one who has felt that way. There are many hemophiliacs who feel that it would be a comfort and they know that we understand and say, "look, it's just better to let us die", you know? Because we are not just a physical burden, but also a financial burden. So,

this is very hard for a mother, you know, because she would never let her son die, never. She would give her life and anything necessary to help him.

Wow, thank you for sharing this. As I said before, you are both inspirations and help the people here so much and the people around the world who can hear your message because there are people all around the world with this illness. We need to learn from each other. Thank you.

Yes, and for us it is really hard to see that in developed countries they can do everything, you know? And when we see... The first time that I went to a world hemophilia conference, and I saw kids running around, playing polo, knowing that my son couldn't even run from here to there, you know?

How old was he?

He was little. My son, this was when he started to crawl. I put him on a thick carpet that I had shipped from the United States, but even with that, he damaged his elbows and knees, just from crawling on the carpet. So imagine the quality of life that he could have. It was nothing. In school, they left him at the side of a teacher during recess. If she went to the bathroom, he would go and play. He could only do that when she went to the bathroom. For him not to be able to play was so difficult. It's as if we want to keep him in a bubble, but it is impossible for a boy.

It is difficult, and dangerous mentally to live that way.

Of course, of course. The life hangs by a thread, right?

Thank you for all that you do. For your work, for your efforts. It is important, and we are grateful.

And thank you to everyone listening to this HemoStories episode. We hope you have learned a lot with us. Feel free to reach out to us on Instagram, Twitter, or Facebook, or on our website at HemoHelper.com. Until next time....