

## Liver Transplantation in Hispanics

Webcast

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### **Jaime Mendez:**

Today we will be talking about one of the most important organs in the human body, an organ without which we wouldn't be able to live: the liver. When the liver fails, we have to do something immediately because the consequences can be fatal. Fortunately, there are certain steps you can follow to improve your condition once your liver has failed.

Today we will be talking with Dr. Juan Carlos Caicedo. He is Director of the Hispanic Transplant Program at Northwestern Memorial Hospital. We are also very lucky to have Maria Plaza with us. She is a patient who has received this kind of transplant and she's going to tell us about her own experience. We will start by talking with Maria. How are you, Maria?

### **Maria:**

Very well, thank you.

### **Jaime Mendez:**

Maria, it's a pleasure to have you here with us. First of all, thank you for your time.

### **Maria:**

It's fine.

### **Jaime Mendez:**

Maria, tell me a little about your experience. How did you find out that your liver was not working properly?

### **Maria:**

Well, to begin with I never realized I had a problem. It all happened very quickly. At first I noticed that my feet were swollen and I thought it was because I was working too hard or because I walked too much. But then my legs became swollen too and I felt fatigue. For example, I couldn't walk and talk at the same time because I felt I was short of breath. And I thought to myself, "How is this possible? I don't suffer from asthma nor have any lungs problems."

### **Jaime Mendez:**

Can you tell me how old are you, Maria?

### **Maria:**

I'm 52 years old now, and I had this condition when I was 49 years old.

**Jaime Mendez:**

And had you always considered yourself a very healthy person?

**Maria:**

Yes, I was absolutely healthy. I didn't have to take any kind of pills, just vitamins. I didn't have high cholesterol or diabetes.

**Jaime Mendez:**

Sometimes a person who is perfectly healthy can be vulnerable to other diseases. So, you realized that you have some kind of problem. You knew that you had no previous diseases and that this is something completely new. So, what did you do, Maria?

**Maria:**

One morning, when I woke up, I went to the bathroom and it was then that I began feeling bad. Apparently, I got very upset by a discussion I had had with my son and at that moment my son realized that something was wrong with me. He said my look was different. He asked me, "Mom, what's wrong with you?" It was then when they took me to the hospital. I acted as if I was drunk—I did things but I was not conscious about what I was doing.

**Jaime Mendez:**

When you arrived at the hospital how did they tell you what was wrong with you?

**Maria:**

I went to the Emergency Room and due to the symptoms I had, they first thought that I could have leukemia or cancer, because my blood level was not sufficient, at least that was what I understood. They mentioned something about my white and red blood cells and many other things, and at first they thought that I could have cancer, a possibility which scared my son. But, they continued running tests and with those results they determined that the problem was my liver.

**Jaime Mendez:**

And what exactly did they tell you they could do?

**Maria:**

At first they tried to put something like a ring in the liver to see if it improved, but the results were negative. So, then one day the doctor told me that I needed a transplant. I felt really scared and terrified and I said I didn't want that. But as time went by, my health deteriorated even though I was taking my medication. I used to come to the Agency feeling really out of my mind. I told my son that I was crazy, but as my son is paramedic, he was able to help me a lot. He told me, "No, mom, you're not crazy, you're very sick." I felt very bad—I couldn't walk, I couldn't speak. It was very hard for me.

**Jaime Mendez:**

Your body just didn't work normally?

**Maria:**

No, not at all. I seemed to be an old lady; I couldn't walk because I felt my body was too heavy, full of water, and swollen. It was a horrible experience.

**Jaime Mendez:**

In a very short period of time, a very healthy and active person such as yourself notices that the body functions begin to deteriorate. When did you modify your attitude towards receiving a transplant?

**Maria:**

I wasn't afraid of the transplant for a long time—it was just when the doctor first told me. I was shocked at the thought of receiving an organ which was not mine. However, the doctor explained things to me and my reaction was good. I felt very bad during the whole year, in 2009, because I slept day and night. That was all I felt like doing.

**Jaime Mendez:**

You didn't have enough energy to function well. Tell me something about the time when the doctor finally convinced you and you felt relieved. How did that happen?

**Maria:**

That was very easy because the doctor is an excellent person and when he told me that for the first time, I reacted saying, "No, no, no, I don't want that." But my daughter, who was always at my side like an angel, also told me, "That's the best solution for you." In fact, when I was admitted here at the hospital, the doctor was always supporting me and telling me that at any moment he could come with the good news, and I felt very calm. I wasn't afraid.

**Jaime Mendez:**

I would like you to tell us something about the time when the surgery was performed and to happened with you immediately after that.

**Maria:**

I was in a coma for seven or eight days, or nine—something like that. I'm not sure about the number of days, but they were quite a few. All I could hear was my daughter telling me that my blood pressure was very high. I don't remember anything about those days; I only know what they have told me. My daughter tells me that when they were waiting for the doctor's report on my condition, they were told that there was nothing else they could do for me. Obviously they felt very sad. I had no knowledge of all this, I only know that the surgery was very long. When I finally woke up, my daughter gave me the good news that I had my new transplant, and I couldn't believe it because I didn't feel anything. I had no pain, nothing.

**Jaime Mendez:**

You had no notion about what had happened.

**Maria:**

Correct.

**Jaime Mendez:**

How was your recovery? How long did it take for you to start feeling normal, and with enough energy?

**Maria:**

The surgery took place on March 15<sup>th</sup>. I remained in hospital until the end of March, and then I spent about three weeks in rehab where they taught me the exercises I had to do. I left the hospital a few days before Mother's Day, in the month of May.

**Jaime Mendez:**

So that you could celebrate Mother's Day in the year 2009, right?

**Maria:**

Yes. I have celebrated two Mother's Days with my children. And I celebrate that day, March 15<sup>th</sup>, as if it were my birthday.

**Jaime Mendez:**

It's as if you were born again, right?

**Maria:**

Sure, my children especially will never forget that day.

**Jaime Mendez:**

Maria, I would also like you to tell me something about your recovery and about how you are feeling now. But first, I would like to talk with Dr. Juan Carlos Caicedo who is here with us too. He's the Director of the Hispanic Transplant Program at Northwestern Memorial Hospital, and he's the doctor who treated Maria. How are you, Dr. Caicedo?

**Dr. Caicedo:**

Very well, Jaime, how are you?

**Jaime Mendez:**

Fine, I'm listening to Maria's story and it's a very beautiful story. I would like to talk with you about this procedure and I would also like to know, from a doctor's point of view, what comes to your mind when you get a new patient. How do you treat that person?

**Dr. Caicedo:**

In the first place, all the patients that suffer liver failure, and in Maria's case it was chronic liver failure (due to NASH, which is nonalcoholic steatohepatitis) is linked closely with obesity, which is a very serious problem in the United States, where around 60 or 70 per cent of the population is overweight or obese. Obesity can affect the liver, generating cirrhosis, which can eventually develop complications.

When the patient develops complicated cirrhosis is when it is necessary to perform a liver transplant in order to save his/her life. In Maria's case, as she mentioned, she was in a coma, one of the phases of the hepatic encephalopathy, for a long period of time. She was very ill. Other patients can develop kidney failure, edema or swollen legs, digestive bleeding, ascites, which is the accumulation of fluid in the peritoneal cavity, portal hypertension, which means that the liver reduces its size and it develops fibrosis while the spleen increases in size. That is why she mentioned that her blood tests were not normal. For example, platelets decrease, and it's all due to the liver failure. Some patients can eventually develop cancer.

When they need the transplant many of the patients are almost dying—that was Maria's case. She was dying because of her liver problem. That's why she was unconscious and she doesn't remember anything. So, when we receive those patients, we always feel distressed because there are too many patients waiting for a liver transplant and very few can be performed, because unfortunately there are very few donors. In the United States there are over 16,000 patients waiting for a liver transplant and we only perform 6,000 transplants per year. More than 2,000 patients die annually without having had the chance to receive a transplant. So, we always feel worried because the patient could die without having had the chance to get a transplant.

**Jaime Mendez:**

Unlike other organs the liver cannot be replaced; however, it is one of the organs, or maybe the only one, that can regenerate. This means that you can receive the transplant from a person who has died but you can also receive a transplant from someone who is alive. Can you explain me the difference between both of them?

**Dr. Caicedo:**

What you have just said is very accurate. the liver is the only organ in the body that can regenerate itself. It is well known for long time, as the Greeks tell us that Prometheus, who had stolen the fire from Zeus at Olympus, was chained to a rock in an island and every day an eagle came down to feed from his liver. The liver regenerated during the night so that the eagle could return on the following day to feed.

Since the time of the Greeks, thousands of years back, we knew that the liver regenerated. So, a donor who is alive can donate a part of his liver. Depending on the recipient, you can donate a lateral left segment of the liver, a very small segment of the liver. If the recipient is a baby, for example, who's dying due to a

fulminant hepatic failure and that segment is transplanted to the baby, the liver will grow to its normal size together with the baby.

Now, if we perform a transplant on an adult, we have to remove usually the right side of the liver from the living donor, and within eight to twelve weeks the liver will grow both in the donor and the recipient. In the case of the recipient, the liver will grow almost to the normal size of a whole liver. The same thing will occur with the donor. We can also perform transplants from dead donors by dividing the liver in two. Due to the liver's capacity to regenerate, we are able to offer transplants to two patients from one liver procured from a deceased donor.

**Jaime Mendez:**

If a donor who is alive can donate part of his liver, why is it so difficult for people to donate their liver?

**Dr. Caicedo:**

Basically, as you said at the beginning of the program, it is due to the lack of appropriate information. That is the main obstacle. People don't know. Regarding the Hispanic population, we are very used to listening to what the neighbor around the corner said, or what the man at the drugstore mentioned, and people start talking about subjects they are not familiar with. As a result, they generate fear and anxiety in the population.

So, the first recommendation in any type of medical situation or for organ donations is to try to approach people who know about that specific subject in order to clear any doubts. Any surgical procedure can involve risks, but the risks are minimal when you go to a place with experienced professionals. So, that's something we have to work on and we really appreciate the task you're doing: educating the society.

**Jaime Mendez:**

What you said concerning education is very important. To that point I would like to mention that not all the hospitals in the United States are prepared to do transplants. More specifically, not all the hospitals can perform liver transplants. Northwestern Memorial Hospital is one of the hospitals that is doing an excellent job and furthermore, there is a person who is in charge of the Hispanic patients. Tell me a little about this program. Why is the hospital putting so much effort on this?

**Dr. Caicedo:**

I'm Hispanic—I'm from Colombia. I used to perform kidney transplants in Bogotá, Colombia, and I decided to come to complete a fellowship and to receive formal training in organ transplants. I wanted to receive surgical training on kidney, liver, pancreas and intestine transplantation, both in adults and children. I was especially interested in liver transplants from a living donor, which is the most complex organ transplant surgery.

I came to Chicago to receive training and during my training, I realized the importance of the Hispanic community but there was no hospital offering focused assistance. I began to look at statistics and I noticed that the Hispanic community is rapidly growing in the United States, even faster than the rest of the population according to the US Census Bureau. We grow at a rate of 43 percent compared to a 5 percent growth of the rest of the population in the last ten years ( 2000-2010).

And our population needs more organ transplants, proportionally speaking, due to different problems, such as diabetes, hypertension, obesity, hepatitis C, which is the main cause for liver failure, and hepatitis B. All those diseases are twice more frequent in the Hispanic population than, for example, in non-Hispanic white patients. So, in talking with the Board of Directors here at the hospital, I expressed this concern. My boss, Dr. Abecassis, who is in fact the President of the American Society of Transplant Surgeons, understood the importance of the Hispanic population and the great need this community. For that reason, they developed a program that was culturally sensitive.

That means that the entire assistance is in Spanish and we have quite a big group. We're 25 persons who speak Spanish. We have two surgeons; we have two hepatologist, one nephrologist, one social worker, one research coordinator, and three transplant coordinators for kidney, liver, pancreas and intestine. We also have one cardiologist, one anesthesiologist, one nurse for post transplant care and 12 nurses on the floor. They all speak Spanish.

**Jaime Mendez:**

So the team is very complete. Now I want to go back to Maria. Maria, you're the perfect example of how a Hispanic person can benefit from a service that is so focused on the Hispanic community, and as the doctor was mentioning, it provides a culturally sensitive approach. Tell me, Maria, how has your recovery gone during the two years since you received a healthy liver?

**Maria:**

Everything is perfect. I do the same things I used to do—everything is normal. I am doing the same job I was doing before. I feel that that year was like a nightmare, as if it had happened to somebody else and not me. I walk a lot now. I love walking and I'm doing that again. I don't get tired and now I can talk and walk at the same time. But everything is centered on that single year. That year was like a curse! But now I'm feeling very, very well.

**Jaime Mendez:**

After you received the transplant how long did it take for you to start leading a normal life again?

**Maria:**

It wasn't easy. When I was receiving exercise therapy that was very hard. I feel as if I was born again. I couldn't even lift a spoon at that time. I couldn't walk and they even had to teach me how to get dressed, how to put on my socks, because I

just couldn't do it. I couldn't even move around on a wheelchair because I didn't have the strength. I was afraid to stand up because I had already fallen down once when I was using my walker. I tried to open a door and I fell to the ground. Nothing happened to me because I had lost so much weight that the fall was not serious. But I must say that I was born again.

**Jaime Mendez:**

I want to ask you specifically about... when you tell me that you were at the hospital for a long period of time, that your recovery was very slow, I want you to tell me how did the staff treat you at the hospital?

**Maria:**

Oh, they were excellent, even though I don't remember much because after the surgery I not very conscious.

**Jaime Mendez:**

But when you asked them they explained to you what they were doing?

**Maria:**

No, I couldn't speak because I had many tubes in my mouth.

**Jaime Mendez:**

And how long did it take until you were able to speak again?

**Maria:**

I think it was when they removed the tubes from my mouth. I can only remember when they told me they were going to remove them, and after that I was able to move my lips, but it's all like a dream.

**Jaime Mendez:**

Now, that first year was the hardest one, but today, two years after the surgery, do you still have follow-up appointments? Do you have to follow any special therapy?

**Maria:**

No, no therapy, I just continue with my medications, which are 3 pills in the morning and 3 in the afternoon—something I believe I will have to continue taking for the rest of my life. But right after the surgery I had to take a lot of medications but the doctors were always checking that they didn't affect any other organ, like the kidneys, for example.

**Jaime Mendez:**

So, you must thank the doctors...

**Maria:**

Oh yes, I'm very grateful to God, to the doctors, and to this place because I'm still at my children's side.

**Jaime Mendez:**

Something we haven't said is that Maria is working at the hospital. It's very convenient when she needs to see a doctor, they're very close to her, they're at hand.

**Maria:**

Yes, for example, I used to have cramps and one day while I was working I had cramps all over my body so the nurses immediately put me on a wheelchair and took me to the emergency room. That's very convenient for me.

**Jaime Mendez:**

That's good service!

**Maria:**

Sure.

**Jaime Mendez:**

Now I want to go back to you, Dr. Caicedo. There are two components here, one of them is the donor and the other is the recipient. I would like you to tell me something about the donor. What does a person need to be able to be a liver donor?

**Dr. Caicedo:**

As we have already said, there are two types of donors. There are deceased donors and there are living donors. Regarding the deceased donors, the most important thing is to understand that we can offer many human beings the possibility to go on living even after death. One single donor can help around 30, 35 persons after his death.

You can donate organs and you can also donate tissue. Which organs can you donate after your death? You can donate heart, lungs, liver, pancreas, intestine and kidneys. You can also donate tissues, like corneas, heart valves, skin, bones, and ligaments. So, one single person can help a lot of people by giving them a new opportunity to live. Therefore, we must express our desire to donate to our family, so that in that moment of deep grief, when we die, we help them make the decision more easily.

And it is important that they know that most religions are in favor of organ donation, both alive and dead—especially the Catholic and Christian religion. John Paul II said that the greatest act of love was to donate an organ. So, it is important that our population be aware of this so they can indicate on their driver's license that they are potential donors.

There are some myths regarding organ donation. People think that if they are organ donors they won't received appropriate care in the emergency room, which is completely untrue. Doctors have the obligation to try to save every patient's life,

but it is only if the patient dies that you can remove those organs. So, the organs from dead donors will only be available once they have died, when the patient is no longer alive. And this is something which creates a little confusion in the population.

And regarding a living donor, we can all be living donors. There are some requirements. . In the first place, you need your desire to do it; it has to be voluntary. You must feel that desire from the bottom of your heart. And second, we must be healthy. If the person is not healthy, he won't be a potential living donor because we don't want to increase the risk of having complications in someone who doesn't need this procedure. There is no direct benefit for the donor. He's just doing it to save another human being's life, which is something wonderful.

So, the donor will undergo an evaluation where we will determine if there is any kind of medical, surgical or psychosocial contraindication. The patient may be physically healthy and he won't have any surgical problems but if he's not psychologically well, or if he doesn't have a strong support network, he won't be a good candidate. So, all those elements are taken into consideration before deciding that a person can be a living donor.

**Jaime Mendez:**

When a person receives a liver transplant, what is the survival rate? How long can he live? What do statistics say about this?

**Dr. Caicedo:**

Basically, those patients that need a liver transplant—like Maria, who was dying, she was in a coma, she was not conscious—the only option to save their life is the organ transplant. It's not like the kidneys when you can keep the patient alive with dialysis. There is no kind of dialysis that can be done to keep a patient alive if he/she has liver failure. So, the only option in that case is the liver transplant. Therefore, it's the only option to keep them alive.

The patient survival after liver transplant has improved a lot and it is quite good. We know that one-year survival after the liver transplant is around 85 to 90 percent depending on the cause of liver failure, age and other variables. After five years we could say it is around 70 to 80 percent, depending on age, cause and other variables.

**Jaime Mendez:**

So, it's quite a high percentage.

Well I want to thank you both very much. I want to thank Maria Plaza, a Mexican lady from the State of Coahuila, in the north of Mexico, very much for her time and for sharing your experiences with us.

**Maria:**

Sure, thank you very much.

**Jaime Mendez:**

I'm very happy for you and I hope you continue with your energy and your good attitude towards this illness. And thanks to your family who have been supporting you so much as well.

**Maria:**

Oh, sure, especially my three lovely children, whom I love very much.

**Jaime Mendez:**

Your angels.

And I also want to thank Dr. Juan Caicedo. Thank you very much for your time and for explaining to us so clearly the different aspects about liver transplants.

**Dr. Caicedo:**

It was a pleasure, Jaime.

For more information or to schedule an appointment with a Northwestern Memorial physician, please contact our Physician Referral Service at **1-877-926-4664** or visit us online at [www.nmh.org](http://www.nmh.org).

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