39 – Roberto D'Angelo and Francesca Fedeli: In our baby's illness, a life lesson

*This presentation was given by non-native English speakers. Therefore, there are some grammar mistakes.

Francesca Fedeli: Ciao. So he's Mario. He's our son. He was born two and a half years ago, and I had a **pretty tough** pregnancy because I had to stay still in a bed for, like, eight months. But in the end everything seemed to be **under control**. So he got the right weight at birth. He got the right Apgar index. So we were pretty **reassured** by this. But at the end, 10 days later after he was born, we **discovered** that he had a stroke.

As you might know, a stroke is a brain injury. A perinatal stroke could be something that can happen during the nine months of birth, er, pregnancy or just suddenly after the birth, and **in his case**, as you can see, the right part of his brain has gone. So the effect that this stroke could have on Mario's body could be the fact that he couldn't be able to control the left side of his body. <u>Just imagine</u>, if you have a computer and a printer and you want to transmit input to print out a document, but the printer doesn't have the right drivers, so the same is for Mario. It's just like, he would like to move his left side of his body, but he's not able to transmit the right input to move his left arm and left leg.

So life had to change. We needed to change our schedule. We needed to change the impact that this birth had on our life.

Roberto D'Angelo: <u>As you may imagine</u>, unfortunately, we were not ready. Nobody teached us how to deal with such kinds of disabilities, and as many questions as possible started to come to our minds. And that has been really a tough time. Questions, some basics, like, you know, why did this happen to us? And **what**

went wrong? Some more tough, like, really, what will be the impact on Mario's life? I mean, at the end, will he be able to work? Will he be able to be normal? And, you know, as a parent, especially for the first time, why is he not going to be better than us? And this, indeed, really tough to say, but a few months later, we realized that we were really feeling like a **failure**. I mean, the only real product of our life, at the end, was a failure. And you know, it was not a failure for ourselves in itself, but it was a failure that will impact his full life.

<u>Honestly</u>, we went down. I mean we went really down, but at the end, we started to look at him, and we said, "We have to react".

So immediately, as Francesca said, we changed our life. We started physiotherapy, we started the rehabilitation, and one of the paths that we were following in terms of rehabilitation is the mirror neurons pilot. Basically, we spent months doing this with Mario. You have an object, and we showed him how to grab the object. Now, the theory of mirror neurons simply says that in your brains, exactly now, as you watch me doing this, you are activating exactly the same neurons as if you do the actions. It looks like this is the **leading edge** in terms of rehabilitation.

But one day we found that Mario was not looking at our hand. He was looking at us. We were his mirror. And the problem, as you might feel, is that we were down, we were depressed, we were looking at him as a problem, not as a son, not **from a positive perspective**. And that day really changed our perspective. We realized that we had to become a better mirror for Mario.

We restarted from our **strengths**, and at the same time we restarted from his strengths. We stopped looking at him as a problem, and we started to look at him as an opportunity to improve. And really, this was the change, and from our side, we said,

"What are our strengths that we really can bring to Mario?" And we started from our passions. I mean, at the end, my wife and myself are quite different, but we have many things in common. We love to travel, we love music, we love to be in places like this, and we started to bring Mario with us just to show to him the best things that we can show to him.

This short video is from last week.

l am not saying --

(Applause) —

I am not saying it's a miracle. That's not the message, because we are just at the beginning of the path. But we want to share what was the key learning, the key learning that Mario drove to us, and it is to consider what you have as a gift and not only what you miss, and to consider what you miss just as an opportunity. And this is the message that we want to share with you. This is why we are here. Mario!

And this is why --

(Applause) —

And this is why we decided to share the best mirror in the world with him. And we thank you so much, all of you.

FF: Thank you. RD: Thank you. Bye.

(Applause)

FF: Thank you. (Applause)