

HABLEMOS AUTISMO: UNIDOS COMO COMUNIDAD TRANSCRIPT

INTRODUCTION TO PODCAST

TONY HERNANDEZ

Welcome to this episode of “Hablemos Autismo”! The first episode of this new podcast and I am honored and privileged to be your host for this podcast, which is long overdue, especially in our Hispanic and Spanish speaking community. My name is Tony Hernández Pumarejo, and I am going to be your host for this new podcast. And I thank all of you who are tuning in to this new life, this new era, and this new episode or chapter in our autism community, especially in our Hispanic community.

So, on behalf of myself and our Autism Speaks organization, we want to thank all of you for being with us on this special day. What an honor to have this episode and this podcast premiering on World Autism Month! This is a podcast for our Spanish-speaking and Hispanic community, and I am honored to host it.

But let's talk first. Who am I? Who is Tony Hernandez Pumarejo? I'm going to talk a little bit about my history. My name is Tony Hernandez Pumarejo, and I was born and raised on the island of Puerto Rico, I am Puerto Rican. And what does Autism have to do with my life? Autism entered my life at the age of 3. And how was that? As part of the life process, I was diagnosed at 3 years old. At one time, which there wasn't, there wasn't much information about what autism is, as there is today.

My parents were looking for answers to the questions they had about me: What was happening to me? That they were seeing something different and were getting different responses. Until then there was a diagnosis of autism. From that moment on, Autism entered my life and as part of growing up as a person with ASD, I face different challenges, common challenges with other people on the Autism spectrum and also faced challenges and situations that may not be common with other people with autism.

I was nonverbal until I was 4 years old and faced different challenges like social communication, severe and social anxiety, and repetitive behaviors. That was some of the challenges that they have been with me in my life and that they even remain with me to this day. But over time, I have been able to go beyond those obstacles and not let them determine my life.

Through my time I faced different situations, both at school and bullying, social rejection, and also different parts of my life. But I also develop different hobbies such as arts, video games, Star Wars, which were not only a hobby for me but also I felt I was entering another world (which is one of the common traits of people who are diagnosed in Autism)

Throughout my life, I faced different and difficult situations. Situations that I wouldn't even wish on my worst enemy. But thanks to having faith and believing in God and not giving up, I was able to keep fighting despite what others said about me.

I continued with my life, and I kept fighting. For example, I graduated from High School with high honors; I entered college and had challenges during this time, which forced me to leave: different situations in my life, clinical depression, mental health; challenges and difficulties in my academic performance. I left college and moved to the United States. It was here that I began a new phase of my life, which was to enter the labor market and get a job. Entering my first job was in an area which, considered according to society a job which people who have Autism, autistic people cannot do or cannot perform: customer service.

I was able to get in and in terms of this job, I felt like I was in school again. I had to deal with different personalities. That is, good people and bad people. Working in a very fast environment, an environment that is fast paced or multitasking. And I honestly didn't think I was going to survive.

I was feeling frustrated and depressed because I wanted to work, because I wanted to keep going and I kept going and I was blaming everything that had happened to me in my life for my failures. Blaming my family, friendships and former friendships; blaming bullies, school bullies; blaming autism, blaming everything, and blaming myself in the end. I felt depressed and frustrated that I didn't have a single place in this world.

But the day came. One day I had to make a decision. And that decision was that I wasn't going to let the differences and circumstances determine what I could do in my life. Whether it was the situation or the circumstances of the outside, I kept fighting and working in that environment that was not favorable, with a lot of stress and anxiety.

I was able to work in that customer service environment for 10 years, including being a manager. Then I was able to go back to college and graduated with my bachelor's degree in business administration with high honors. Including being recognized by the president of the University as an autistic college graduate and that was a very important moment in my life.

Because then it was confirmed what it has been and what my life mission is: Which is to make a positive and lasting difference in the autism community and people who are facing challenges. And I've done it through different projects that I've done, like being a writer of my own book, being a motivational speaker and doing presentations all over the United States, different parts of the world.

And working even to get to something that I did not even imagine was going to happen not only being on television, but also work in television. I was on TV for two years, which was a unique experience. It let me evolve as a presenter, a journalist. I interviewed different people from the autism community all over the world and public figures on my program. That program was for the entire autism community. I've done podcasts, I've done writings and today I'm working and I'm part of this great Autism Speaks organization.

And that's why we're here today. That's why we're doing this new podcast, "Hablemos Autismo". Because the Spanish-speaking and Hispanic community needs a voice. They need a voice, and we are here in this space, in which we are going to talk about the purpose of this podcast: to create awareness of the challenges that people and families living Autism face in their daily lives, especially in our Hispanic community. Many of these issues also impact the autism community of other cultures, other races, and other languages.

We're going to talk specifically about challenges within our Hispanic community. And this is going to be bringing as guests not only families, parents, but we are going to bring as guests autistic, professional, all speaking adults.

And we are going to have this space to be able to talk about these issues and not only talk about these issues, but more importantly: what we must do as a society to be able to create and give these families a better opportunity to be able to fulfill a better quality of life. And that's why this podcast was created, Hablemos Autismo.

I always go for these four principles: acceptance, awareness, commitment, and action. It's what I bring to my mission as a person who was diagnosed with Autism at 3 and Asperger syndrome later.

And I carry my mission for this community that I appreciate so much and that has given me the desire to continue living and that has given me purpose of life.

And that's why we're here.

This is going to be a podcast for you. Any questions, comments (positive or negative), I am here to listen to you, I am here for you.

So, on this World Autism Month, we're not going to wait any longer, let's start our podcast, Hablemos Autismo!

And thank you very much for tuning in today...

TWO MARATHON RUNNERS, MOTHER AND DAUGHTER: INTERVIEW WITH KARINA AND SAMANTHA RODRIGUEZ

Tony Hernandez: In this special episode of Hablemos Autismo and especially in relation to World Autism Month, I have the honor and privilege of interviewing two marathon runners, but they are not just marathon runners, but it is a mother and her daughter. This is the story of Karina and Samantha Rodriguez. Living in the City of Orlando, Florida, they are examples of inspiration. And what better in this World Autism Month for them to talk about their story, so I have the privilege of having Karina and Samantha today. Thank you for being in this episode of Hablemos Autismo!

Karina Rodriguez

Thank you very much Tony for having us. And it is a pleasure to be able to talk with you and to be able to share our inspirational story.

Tony Hernandez

It is my pleasure that both of you are here because in our community needs to know your history. A little bit of this story, Karina, your daughter Samantha was diagnosed with Autism. At what age?

Karina Rodriguez

She was diagnosed with Autism at age 2.

Tony Hernandez

Ok and when you received this news back then, what was your reaction? To the news that your daughter was diagnosed with this thing called Autism.

Karina Rodriguez

Yes, when she was diagnosed with Autism, I felt that my World has ended, because she was the first child I had. I was only 25 years old and I always wanted to have children.

So, she was my first child and when the neurologist told me that she had Autism, I didn't understand much about Autism, because since then people didn't talk much about autism. I felt lost, I felt like I had

no answers. It even got to the point that I felt that I was blaming myself; that maybe I felt that I didn't take good care of myself during my pregnancy and the neurologist told me that while she was going to grow and develop, she was going to get worse and she wasn't going to be able to live a normal life like the others.

Tony Hernandez

I imagine that was difficult Karina. Receiving these comments and I understand you as a single mother facing those difficulties of helping your family by working and giving them a better future.

In the face of these challenges, what was that defining moment that changed the trajectory of both you and Samantha in this process? Because I know there was a moment and you put the criticism you were receiving to be able to move forward and be able to help your daughter move forward and have a better quality of life.

Karina Rodriguez

Exactly. What happened is that Samantha was born in Miami, and I had all my family living in Orlando. So when I had the second child, I felt completely alone because I was raising Samantha and a newborn. My parents offered me to move to Orlando and I moved with the two girls to Orlando and there I realized that there were more services than in Miami.

Here in Orlando, I had to start from scratch with no job, nowhere to go and I started to find out what associations there were about autism and Samantha was able to take more therapy here. In a therapy that I was taking because I was in depression, I felt like I didn't know how to help Samantha. Then I started running. It was like therapy for me and then I started riding in a group of runners. And that helped me to think about other things. It was like therapy for me.

Tony Hernandez

Ok and now for you Samantha. If you can explain a little about how and when you were growing up or in your childhood to talk a little about your hobbies. What did you like to do?

Samantha Rodriguez

Paint.

Tony Hernandez

Paint, wow that's great! So, you had different hobbies. Karina and Samantha, when did this passion was born in regarding running marathons, how did this passion start?

Karina Rodriguez

Yes, it started when I started running, I traveled and sometimes there were marathons that were in other states. I took Samantha with me because she likes to travel a lot and I take her to get these experiences. Then she came and she was like a spectator and she was waiting for me on the line when the runners came in to finish line. In 2016, I ran the New York City Marathon.

I remember I took Samantha, and she was waiting for me on the finish line with my sister. And when I crossed the line and they gave me my medal and I remember that she told me that one day she would like to run and also have a medal like mine and from that day our journey began.

I decided that I was going to help her, that I was going to train her so that she can achieve her dream and I said, if I can run I know that she can run if I guide her. Then we started walking together, sometimes walking on a block.

And then she progressed little by little until she began to run marathons in the community. And I saw that her coordination was improving, she didn't fall much anymore because when she was diagnosed with Autism she tripped over chairs, she tripped over people, she didn't have much coordination and that she suffered from that for many years because their muscles are very weak.

I thought, maybe if she starts running, that will make her stronger. Well, she can be with more people because sometimes she bumped into people because she couldn't coordinate well; she ran with so many people that she was getting better. Then she began to be with people and no longer hide.

I feel that running was great therapy and at the same time it was therapy for both of us because we can do a hobby together. And it's bringing us closer and we're closer together and I understand now what she's going through and I get into her world, and she's taught me a lot of things. I know she never gave up.

For me she is my inspiration every day and that's why I keep going and I think that she also needs opportunities like other people.

Tony Hernandez

Exactly, this process of running marathons helped.

In terms of overcoming those barriers, overcoming those challenges, both of you went beyond the limits of the condition and are a living example of that. We saw how not only this process helped Samantha but also helped you, Karina.

In this process of being a better people and keeping in mind that no matter the difficulties and challenges, it is impossible. Everything is possible in this life if one proposes it and going along this line, I have been curious with a question that I wanted to ask you, that is, you participate in different events whether it is the New York race or the Boston race or the London race. Do I understand that you will soon be participating in a race in Chicago, correct?

Karina Rodriguez

Yes, in October.

Tony Hernandez

Perfect.

Tony Hernandez

So, how do you feel when you're running in front of a lot of people? ¿don't you get some anxiety or nervousness? ¿How do you, not how you handle it?

Karina Rodriguez

Yes, it's a lot of preparation, because also mentally Samantha had to prepare with the changes, because when we go to a city very different from Florida, maybe the weather can be colder or other type of people. But the good thing is that with the training that we do here, I have trained her in all kinds of temperature and that she has a behavioral therapist, who also works with her.

Karina Rodriguez

About the changes of what there may be. Because I feel that when you go to a race that everyone is different and also at the same time, we know with a purpose that we want to represent our autistic community.

That when we run together, that we are here going with that purpose, and we feel proud because they are half of runners and we always carry the symbol of Autism. But it has cost her a lot, because as she has difficulties with muscles and then, she must work twice as hard as anyone who does not have any disability.

So, her training costs us too because I work full time, I also must take the time after working to be able to go to training with her. She goes to school and after school she also must get to training.

But her dream is to be able to do all the marathons in majors. It's her dream. As I tell her that, never give up, even if it takes us more years, but I know that we can achieve it because everything is possible.

Tony Hernandez

Everything is possible with God's favor; everything is possible, and you set the goals and have fulfilled them. You have broken barriers and will continue to break barriers making that difference because your mission is beyond, it is a community that you are fighting for and representing in all the events that you do as part of advocating for our autism community, and that is what brings us to this Autism month.

For as you know, this month, which creates awareness of autism and how autism impacts individuals and families; also, about the urgency and what we have to do as a society to be able to help families impacted by autism, to have a better quality of life.

I ask you, Karina, with your experience as a mother and teacher also to your daughter Samantha and experiences that you have lived, ¿how would you define autism today?

Karina Rodriguez

I think that Autism, that it is growing more and that there are more in children and that they are being diagnosed with autism and I feel that we are a community that we have fought so that the community can be including us; Because sometimes we don't feel included because we are different. Then our mission is that they accept that autism and that they have the right to live a quality of life.

And to achieve their dreams, but what they need is only a chance, because I know that every child with autism has a talent. And, when they teach the talent that they have, that they shine. But they need the community to include them and give them opportunities.

Tony Hernandez

Exactly and within and as we know, this is World Autism Month.

As a last message, what message do you have both Karina and Samantha to those parents, to those families that you are seeing in this interview right now, to those mothers who may be going through what you have gone through with your sons and daughters? What message would you have to those families right now?

Karina Rodriguez

Let the message be said to never give up for your children, because they depend on us. They depend on us to advocate for them. That would be the message and I know that there will be many obstacles, because I had them as a single mom who is raising two girls, but nothing that is impossible.

There is always a way to find help for them, it can be in sport, it can be music, but there is always a way for them, but we must advocate for them. Because they depend on us, and nothing is impossible. Samantha was diagnosed at age 2 and doctors had no hope for her. They told me that she could never walk, that she was going to keep falling, that she was going to keep stumbling; that I had that when she was an adult, if I was going to put her in an institute, that I had to prepare for that; but I decided, that I was not going to give up. Because sometimes it's very easy for a person to give up because sometimes what you hear from doctors or the community is sometimes negative, but it's up to you to make that decision and say I'm going to fight for my son or my daughter and I made the decision that I wasn't going to give up. They had no hope for Samantha.

And I know and I saw her that she fell a lot and tripped over the tables and chairs, but I decided that I was going to be her therapist. That I was going to be her teacher and that I was going to help him walk. And today Samantha is 20 years old and has already run 3 marathons. And years ago, I was told she would never be able to walk.

That to me is a testimony that if they told her that she would never be able to run and she would never live a normal life. My testimony is to never give up because today she is traveling to other states and running marathons. You are no longer tripping over tables, or chairs. Anything is possible, but you must have faith. A lot of faith.

Tony Hernandez

Exactly and Samantha, do you have a message for our autism community from you?

Samantha Rodriguez

Never give up.

Tony Hernandez

Exactly, never give up.

Perfect and one last question, Karina and Samantha, do you have social media? or website? How can our audience listening to and watching this interview know about you or how to support you in this mission that you have with our community?

Karina Rodriguez

Yes, Samantha has a page, which is "Samantha's Running Adventures, Every Mile for Autism Awareness" Also, she has her own Facebook page and she shares all the marathons and races she does with autism.

You can follow her on her page or you can follow me on my page. Karina Rodriguez, which I have a Facebook page.

Tony Hernandez

Excellent, your story is very inspirational.

You are a great example and not only what is our community, Autism, but in society. We need more people like you. Mothers and daughters who despite the difficulties, despite the challenges have not let those remains put limits on your life. You have gone beyond your limits and will continue to do so and always the best wishes so that you can achieve those goals that I know with God's favor you can achieve. Thank you so much Karina and Samantha, it was my pleasure that you have been with me today in this first episode of Hablemos Autismo and continue to make a big difference for our community and our world. I appreciate you being with me today on this episode!

Samantha Rodriguez

Thank you so much!

Karina Rodriguez

Thank you very much Tony!