

**UNDERSTANDING DYSPHAGIA:**  
educational booklet for parents and/or  
caregivers of children with

# *Cerebral Palsy*



**Understanding dysphagia: educational  
booklet for parents and / or caregivers  
of children with cerebral palsy**

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# PRESENTATION

This educational booklet presents the story of Rebeca, a premature baby who overcame dysphagia.

We dedicate it to all the children and families who struggle to overcome childhood dysphagia and to all those who tirelessly dedicate themselves to the rehabilitation of these children.



# Hi, little friends!



Has any of you ever heard of miracle? My mom tells me I'm a true miracle. And soon enough, you'll find out why.



My name is Rebeca! I'm 4 years old and today I'd like to tell you a little bit of my story! With my mother's help, of course.

Well folks! I was in a hurry! And for a very good reason, our Heavenly Daddy ordered me to be born ahead of time.



Have you ever heard that babies born prematurely need special care? It was like that for me.



My mother told me I was born at 23 weeks of gestational age. As soon as I could eat, Dr. Kehdi put a small tube in my mouth, where I received milk that helped me gain weight. It was a joy for Dr. Kehdi, my neonatologist.



Mommy would visit me every day! I calmed down when I heard her voice! It was such a thrill when she held me for the first time.



Folks, you can't imagine how I feel when I ask my mom to see the first photo I took with my dad!!! I miss him so much!



# JANUARY 2017

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These were three important months for me and for everyone in my family. Thank God, we, premature babies, are very well assisted!

To kill time when I asleep, mommy talked to other mothers who, just like her, accompanied their babies.



Mommy became friends with Ms. Rodrigues, Isabela's mother, and Ms. Barbosa, Felipe's mother.

Before going home for good, breathing on my own, without any equipment, Dr. Nunes, my speech therapist, talked to me every day while giving me some milk from a bottle, since I couldn't breastfeed.



At first, mommy said it was hard for me because I was so tired! But with Dr. Nunes's persistence, I was able to drink more and more milk each day.



Imagine the emotion my mom felt when Dr. Nunes told her she would start feeding me herself!

The hospital team could finally think of sending me home! But I was only discharged after BERA.



Mommy told me that Dr. Elpídio, my physiotherapist, made sure I learned to breathe on my own. She told mom that I would need help to learn a lot of things after discharge.





Dr. Teixeira, my eye doctor, also took care of me. As soon as she realized that I had retinopathy of prematurity and congenital cataracts, she referred me to surgery.



That's right, you guy! Anyway, I was home and as soon as I was able to go out, mommy started taking me for early stimulation in this super nice place!



Mommy says that everyone, welcomed us there.



As I was still little and couldn't support my head very well, mommy was worried because sometimes I choked and turned bluish.



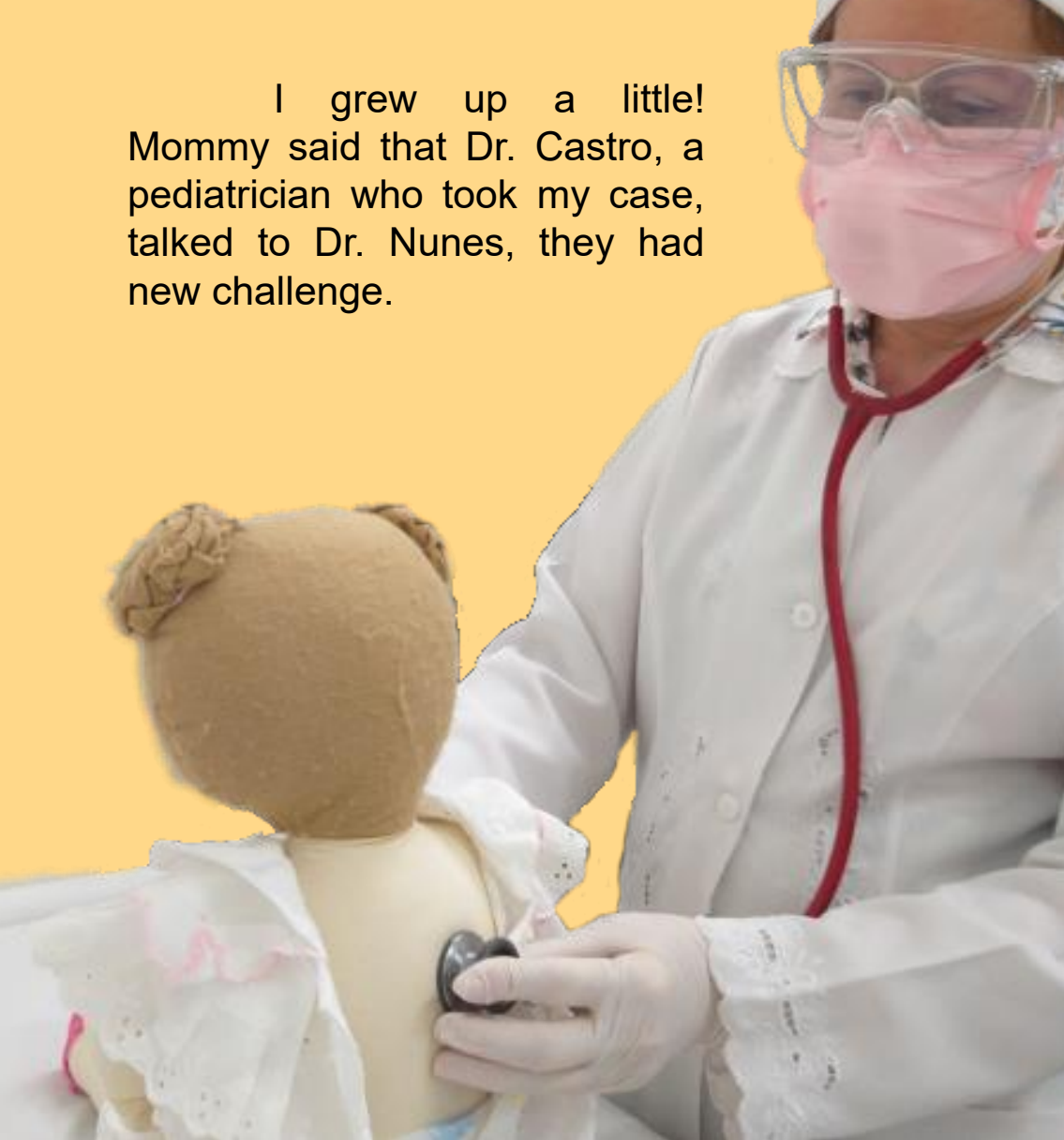
There we found Dr. Nunes, who and recommended we changed the feeding bottle. She also instructed mommy to hold me in a sitting position at a 45-degree angle and to pay attention to my breathing.

All this care was so that I could drink my milk safely! And then burp!



You guys, mommy learned right.

I grew up a little!  
Mommy said that Dr. Castro, a  
pediatrician who took my case,  
talked to Dr. Nunes, they had  
new challenge.



It was time to get to know the world  
of flavors, textures and smells of fruits. It was  
such an adventure! Many surprises and  
grimaces!



Mommy bought a small shallow spoon to take to therapy, and Dr. Nunes started to offer me scraped fruit, always placing it in the corners of my mouth.

Oh my, you guys! I spat everything. But practice taught me to swallow without choking.

Mommy said I'm Super Rebeca! And she's my heroine.



She was very happy when Dr. Nunes allowed her to start feeding me fruit at home.

The next challenge was when Dr. Monte, the nurse who accompanied me, allowed me to have soup! I thought, “Oh my Lord! Why do I have to eat this?”



Dr. Nunes has so much to tell about it! She always explained to my mother that, as I already knew how to suck and swallow properly, I then needed to learn how to chew.



Can you imagine how the introduction of the mashed fruit and soup was? Oh, my!! Each change made me start choking again. If it weren't for my speech therapist's advice, it would have been more frustrating, both for me and my mother.



Today I eat everything! And I like to eat alone!

Do you remember Mrs. Rodrigues, Isabela's mother? What a small world! Mommy said she found them again at early stimulation.



Unlike me, Isabela only accepted thickened liquid food and sieved fruit and soup. She was allergic to cow milk and regurgitated her food.

Dr. Nunes instructed Mrs. Rodrigues to add thickener to the water and to thicken the milk in order for Isabela to swallow safely.



Mrs. Rodrigues bought a bottle teat with a hole for thickened liquids, just the way Dr. Nunes recommended. And she adapted the cup.

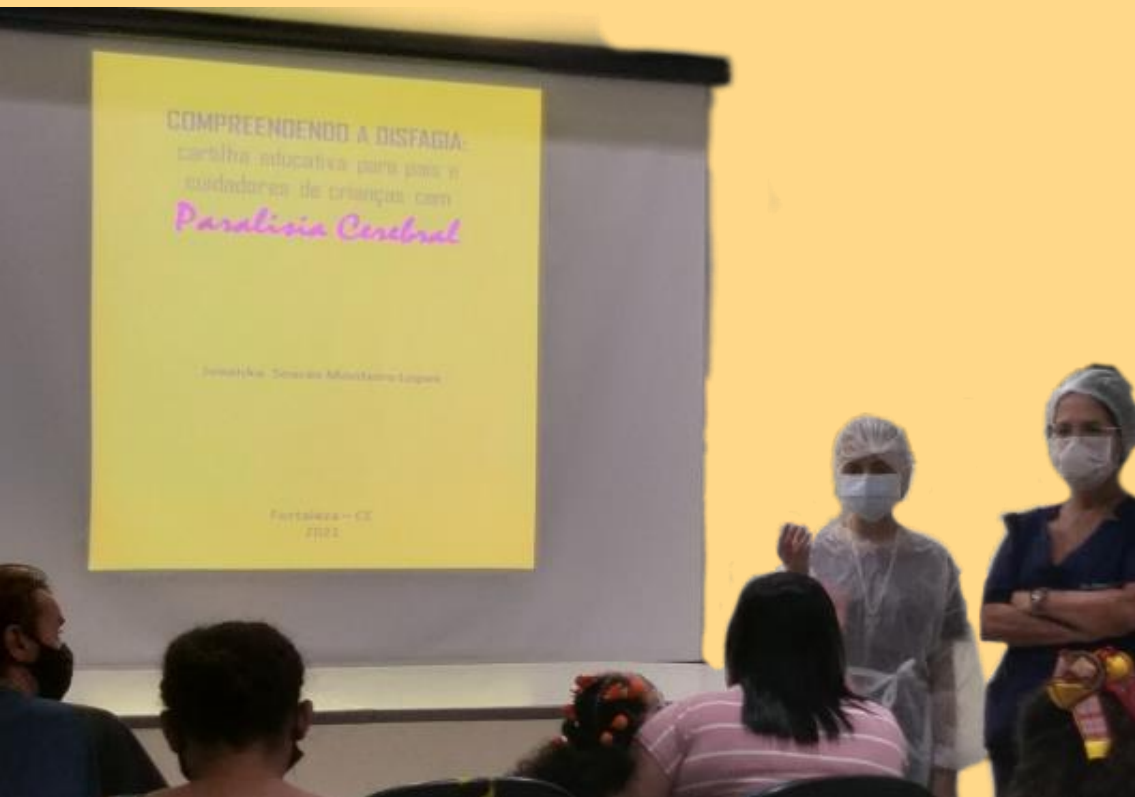
You can't imagine my mother's joy when she also ran into Mrs. Barbosa again, Felipe's mother.



My little friend, different from me and Isabela, was discharged from maternity using a feeding tube. Dr. Nunes soon recommended an evaluation with Dr. Tavares, our ear, nose and throat doctor who recommended a gastrostomy.

Mommy said Mrs. Barbosa cried a lot with the News, even though she knew the cause of all Felipe's pneumonias were bronchoaspiration.





Mommy told me that at Early Stimulation there was an advice group with the mothers of children with dysphagia, coordinated by Dr. Nunes e Dr. Magalhães, our psychologist.

This was how Mrs. Barbosa heard the testimony of other mothers, who spoke of the benefits of the gastrostomy for the lives of their children. They were now healthy, gaining weight, well hydrated and with more energy.



Mommy said this was importante, and as soon as Felipe started to be tube fed, Mrs. Barbosa received the related training.

Mrs. Barbosa takes special cares when feeding Felipe and offering him medications.



She's careful when bathing Felipe, so he doesn't pull the probe. Right after the bath, she carefully dries the skin around the probe, paying attention to any signs of irritation or infection.



Oh! I almost forgot! Mommy told me Mrs. Barbosa pays attention to the deadline for changing the probe and has already bought a protective band at NUTEP's workshop.



This way, it's safer for Felipe to do many activities at home and at the Stimulation.

Well, everyone! After our conversation, you can imagine why my mother said I was a true miracle. I beat dysphagia, but our journey continues!



After all, Dr. Magalhães continues to follow up with me, so that I can overcome the social isolation caused by the pandemic, as well as missing my dad, who now wins medals in heaven.

# ABOUT THE AUTHORS



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