

WE ARE ONE

Alicia Ayora Talavera

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We are one  
by  
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Carlos is an extension of my being; talking about me is having to talk about him.

How to remember things from fourteen years ago or more? Many times I thought about writing a personal story since the birth of my son Carlos, possibly because of the need to talk, to share my process not only with people who are going through a similar situation, but also with those who have had the curiosity to know and with those who, upon finding out, have felt uncomfortable for not knowing what to say, when in fact I do not expect them to say anything. Sharing my experience has been therapeutic, it is something that has helped me enormously to feel and keep me in a place within the world that surrounds me.

I have always thought that life is something worth living, so I have intensely enjoyed what it has brought to me. I can not even remember or think in tragedies, or situations that I have lived as such; things have come and I have taken them as they come. Nothing difficult that had happened to me in life could steal a pinch of my desire and pleasure to live. I love life. I think that a lot of this has to do with the family that I was lucky to have, I learned about love and respect to my sisters as something fundamental: never hurt their feelings with words or attitudes. The teaching from my dad in this apprenticeship, when there was a fight

between sisters, was to remedy it with kisses, hugs and apologize. I suppose that this has been the basis for me to relate with life in general the way that I do.

Thinking about my parents and my sisters has always made me sigh and feel that having them fills my lungs with air. All this is the only concrete explanation that I can give myself about if what I am has been determined by these people.

I am forty-two years old. I was born and lived for my first twelve years in Mexico City, D.F., and since then until today I live in beautiful Merida. I was a happy child with five sisters, three older and two younger than me, and when I was twenty-one, the sixth of them was added to the list.

Despite growing up under the influence of the catholic religion, I questioned many things and I always felt free to think. At the end, nobody could know what was going on and goes through my head. My parents gave me confidence and made me a free woman in many ways; if I expressed some of my doubts, they never forbade me to have them or do them.

Thousands of ideas spun in my head, but they did not go out from there. There was nothing yet that would give them form, name, structure, they were just questions or thoughts. I think that they taught me to see things without malice, naturally, perhaps with less prejudice than others.

One of the things that I have always done when I am sad, hurt or with some feeling that disturbs my peace, is writing how I feel. Since I was fifteen years old until when I was nineteen, I had my diary, although in that pile of notebooks I never put many things out for fear that someone would read them.

Fortunately, the benefits of technology allow us to save paper and to save stories under passwords without much risk of someone reading them. Now, I can unleash my imagination and write all kinds of things, some pleasant ones, and others not so much.

At the age of nineteen, I began my relationship of courtship with the person with whom I have shared more than half of my life, a relationship that for many years, fortunately, the low blows reinforced it, especially the most difficult times.

I studied the bachelor of Tourism Business Administration, not because it was something of my interest, but because, at that time, the Physical Education course was not a degree, and my interest in Veterinary Medicine was limited by the allergies that I developed due to the climate of Merida since we came to live here.

Therefore, with the haste to choose when I finished senior high school, the safest option to study something and not stay in the anything was administration. In this period of time I met who my husband would be and we were sweethearts during the

last three years of the career. When we finished it, we got married. I was only twenty-two years old.

I got married, like most women, believing that marriage was the most wonderful thing. Before my first pregnancy I was working in a travel agency, and from there came the opportunity to enter to a company in the Human Resources Department. When I got pregnant, they kindly invited me to leave. So, I left the beginning of a professional life and became an authentic housewife.

Among all the joys, good times, misfortunes and disappointments of a relationship, after three years of marriage I had my first pregnancy. Everything staggered, I suppose because of the fear of the responsibility of what was coming; I was just disconcerted. The period of pregnancy was not pleasant physically nor emotionally. I went up sixteen kilos; the first two months I already had five more kilos, my belly and my breasts grew exorbitantly, my hands and feet increased in size. That little virgin body lost its shape, and the layers of smooth skin of my abdomen began to break leaving hundreds of scars.

On March 1<sup>st</sup>, 1991, Ray was born. How strange it was to have in my hands that person who I felt that I loved before he was born, with whom I built stories and who I imagined in many ways, and who turned out to be a stranger! I can not deny that I fell in love in a few days by seeing him so helpless, small and in need

for care. All dreams built before I had him in my arms were lost; the result of the new ones was and is much better.

In the first months I realized that my son made me feel invincible, strong and brave, full of life. There was not the slightest fear of traveling a road alone, if it was necessary. After giving birth, a new wave of painful feelings came when I found myself physically different, unwanted, reason why I swore to myself not to have another child.

Based on my desire – or would it be that of the others? – of being a good mother, I thought about starting a business that would allow me to be with my son and to take care of my house.

Taking advantage of the fact that before pregnancy I had the opportunity to study physical conditioning and receive an international certification, in addition to the liking and discipline with which I have always dedicated myself to sports, I decided to open a gym.

Once inaugurated, I devoted myself with all my strength to raise it. It was almost three years of work in my business, and on the way came the idea of having another child. I thought about it a little bit, but finally I decided to do it, assuming that this time it would be different. I would be careful not to gain extra kilos. I made enormous sacrifices not to put on more weight than the necessary, and to feel physically attractive



even while I was pregnant. This time I did not want to feel myself humiliated again by the kilos.

After the birth of my second child, I realized that the first one was not only a gift from life, but it was and is the best thing that could ever happen to me: Ray is a child endowed with sensitivity and kindness that seemed to have arrived with the mission to prepare me so that the near future would not be harder for me.

There are scenes of my second pregnancy that I remember very vividly and are those that relate to fear. One of them was in July, after a vacation where I was lying on the beach tanning, as I used to do every year. Days later I found out of my pregnancy and for weeks I was worried that the exposure to the sun for so many hours would hurt the baby. Finally, the fear passed. I was happy. Ray, my oldest son, was three years old. Carlos would be born in March, the same month as him, but a few days after.

I also remember the poisonous comment of a gym client about the risk of my son having a problem as a consequence of so much Diet Coke I had drunk before my pregnancy. This fear was more intense, but it lasted less, since I could not spend my time thinking about the risks to which I had exposed myself to. I focused my thought that everything would be fine.

Everything happened normally the first three months, until I began to feel that my abdomen was hardening and I was afraid. At the monthly

appointment, the gynecologist explained to me that the symptoms were of contractions, so he recommended taking a medication and exercising with less intensity. At that time, with a lot of effort, I began taking care of my diet and tried to take it very light with the aerobics.

Everything was calmed for two months; at five, the same symptoms returned. I went back to take the medication and the exercise routine was even lighter. As I had not gained more than the kilos advised, I felt very agile and happy not to see myself as fat as in the first pregnancy. This worried me, since my body was, in the world of physical conditioning, my instrument of work.

Among the things that I thought about in this new pregnancy, was, of not breastfeeding the baby, since my experience with his brother had been traumatic, starting with the breasts that became so big and because I had milk for more than a year and a half. Of course, that idea was inside me and I never mentioned it because of what it implied socially. The only nice thing about the first pregnancy was to listen to his heart, to see him in the ultrasounds, to feel him moving and to experience all those physical and emotional connections with him.

After Ray, my body acquired a huge sensitivity. I could feel the movement of my intestines, of my stomach, so in the second pregnancy I felt physically more connected with the baby. One of the things that

was very evident was our taste for the same music. Carlos moved more than Ray, he frequently seemed to tap me repetitively making me feel desperate, and I had to rub my belly and move myself abruptly so he would calm down. When I listened to music that touched my senses, Carlos reacted. I guess that the pleasant feeling for me was also for him.

In the repetitive attempts to be born before time, and according to the calculations of the doctor, for the Easter holidays of 1997, with only eight months of pregnancy, at the baby shower that my family and friends organized for me, the contractions began again and they did not stop.

That day, since morning, I had an enormous difficulty when walking because of the pain that I felt in my groin; I did not imagine that it was a sign of premature labor. Nervously, I called the gynecologist to inform him about the contractions. He recommended me to take times in the meantime and to meet him at the hospital at ten o'clock at night. I did not even have time to taste dinner and the party was over just after having started.

I was very happy, and after almost six years of marriage, Carlos was born, my second son, who absorbed all my strength during delivery to be able to be born and who, a few days after he was born, he began a struggle to survive.

The moment of childbirth was very distressing. Who would have imagined that our history of ups and downs, of going and coming, of navigating between tranquility and anguish, was beginning. I never imagined that once it was time to go to the operating room, my life would take a different path to the one I always followed calmly, without any blow to the face and without major problems. My husband came in with me. My sisters watched from the outside with the filming camera in hand.

Everything seemed normal, until the number of times that they asked me to push began to exhaust my strength. I noticed the concern in the voices of the doctors and in the hand of my husband who pressed stronger and stronger my hand.

I remember the moments of tension. Once or twice I looked at the door of the operating room and saw the face of my sister that was watching with bewilderment what was happening inside the room, with the camera suspended in the hand.

With voices of anguish, among the doctors said that the baby came with a knot in the cord that did not allow him to come out and that was why it was being so hard for me.

I started to exasperate. Each push was becoming weaker, and in my head the only thing I could think was that I could not do it one more time. The idea of giving up, like a gust of wind went through my mind,

and it was in that last attempt – which required from all my exhausted strength, accompanied by the feeling that this would be the last time that I could do it – when Carlos was finally born.

I remember clearly the voices of the pediatrician asking the nurse to give him this and that, meanwhile he smacked the baby's buttocks who was not crying and could not breathe. The pediatrician was with the baby behind me, so I tried to see what was happening to him by turning around every time I could. In one of those moments, I saw a little body starting to turn purple, and all the voices, the light, the breathing, the sounds of the instruments and the anguish filled my head with chaos during the eternal minutes that they took to make him breath. While I asked what was going on, without letting go of my husband's hand, who was as pale and scared as I was, I finally heard a weak crying and he was taken away immediately.

Now that I remember it, I never imagined, in the following hours, what each of the seconds that encouraged the birth of my son would imply. I was taken to my room, and the baby was taken to the incubator so that his temperature could stabilize.

I slept very calm and, the next day, calmly, they brought me the baby who barely sucked. The pediatrician visited me and never mentioned the possible neurological consequences due to what happened, he only told me that the baby was stable,

but that his temperature was slightly elevated, that was the reason why he was left in observation for a few hours.

We were not even twenty-four hours in the hospital. Next day in the afternoon I was able to go home. It was the Easter Holidays vacations, so the first place Carlos knew after the hospital was the house of his paternal grandparents on the beach, a place that in the future would become very significant because of the painful events that occurred in it. Two days later, he started with cold symptoms and we took him to the pediatrician. He started with medications only forty-eight hours after birth; this is another part of the story that I regret a lot.

The days passed and the cold got worse, he had stuffy nose, and his eyes filled with green rheum, to such extent that he could not open them. More medicines, we changed doctor, and diarrhea began with the antibiotics. Prescriptions and more prescriptions!

Two months went by without improvement, until a neurologist friend of mine told me that possibly it was a bacterium that the baby caught in the hospital, and that he needed very strong antibiotics to eradicate it. Indeed, after several cultures, the type of bacteria was identified and we had to bombard his little body with antibiotics.

It took four months to end this problem, without knowing that we had already generated another one in his intestines. I try to remember my emotional state in those moments and the only thing I remember is a blocked anguish; letting it out was a risk to move forward and resolve what was happening. There was no time to lose.

Over the weeks, even without knowing the possible consequences of hypoxia – of which the doctor did not tell me either –, as a second time mother, I was on the lookout of every movement and changes in the baby. I was waiting the stage of the first weeks, when his skin peels and then it becomes smooth and softer. After this stage, the baby had some stains on the skin that seemed strange to me, but nothing that I had to worry about. I saw them since the beginning and I thought that they would go away with the skin change. Not only did they stay, but his head also started to warm up and he started to sweat abnormally.

I went to a dermatologist known by my in-laws. After explaining him my concerns, he took out some large books that he accommodated in his desk and began to read me about a degenerative disease called *incontinentia pigmenti* that only men suffer. Faced with this affirmation and coming from a doctor, I left from there devastated, thinking a thousand things and asking myself others.

When I got home I phoned my husband, and he called his father, who spoke directly with his friend, the dermatologist who had made the diagnosis, and who retracted from his affirmation and suggested that it was only a possibility.

In my desperation to understand what was happening, I searched the internet for information about the syndrome. One of my sisters who was living in London at the time, put me in contact with a person who explained to me by mail about Hypomelanosis of Ito and its difference compared to the incontinentia pigmenti. Carlos would not have survived the last one because it is lethal in males a few days after birth. At least in that part, my husband and I felt calm; however, the surprises did not stop.

The journey began among geneticists, neurologists and the pediatrician. This last one, was a sad sample of the dehumanization of some doctors. He never believed me or gave importance to my observations of every second about my son, until his head grew four centimeters in just one month. It was then when he decided to send me with the neurologist. This one, after diagnosing an evident slowness in his reflexes, asked for a tomography, which not only gave a turn to everyone's life – starting with Carlos's life –, but also twisted and tangled it like a rope, leaving us all knotted.



At that time, I needed a professional to tell me something that would calm me down, so I went to see a neurologist, friend of my sister, who had recently arrived from Cuba to settle in Merida. I remember that after I explained to him the situation, he said to me not to worry, because Carlos smiled and that was a good symptom. I left from there very calmed, ready for the scheduled studies.

On the day of the tomography, my husband and I arrived nervous to the doctor's office. Carlos cried of hunger, since he had to be fasting. (I did not think that remembering this would hurt me as much as I am feeling it. Damned be that moment.)

I went in with the baby and helped to accommodate him in the camera. He was very scared, he was screaming, so the doctor asked me to leave and to leave him alone with the baby because they would have to sedate him. Trusting on his experience and the title of doctor, I went out of there against my will and sat down with a suffocating anguish to wait. Carlos stopped crying and, about twenty minutes later, they called me and gave him to me.

Taking advantage of the fact that he was still asleep due to sedation, we went up to the ophthalmologist to have him do an ocular fundus study. The ophthalmologist's office was full, but they gave up a place for me when they saw me arriving with the baby. Carlos was only five months old. After a few

minutes of sitting down, I felt that Carlos became hard as a stone and I noticed that he was not breathing. I can not forget how, in a matter of seconds, his body relaxed in the dream, passed to that hardness, as if all his muscles were contracted, which in fact they remained that way; his face was totally still. God! I got up suddenly, almost screaming that the baby was not breathing and the doctor came out immediately, he tried to revive him, took him from my arms and we ran out of the office to go down three floors and get to the emergency room.

While we ran, I did not know whether to go by the elevator or by the stairs behind the doctor with Carlos in his arms. I was blocked and desperate to arrive; Raymundo and someone else were behind me. I do not know how long it was. The time factor is something that, since the birth of Carlos, it is a giant word in my head.

When we arrived at the emergency room, the baby began to breath. I did not see what they did to him because they left us out. I cried while thinking that it was not possible that things were getting more complicated. Already with an idea of the consequences of a brain injury due to hypoxia, the doubt of what would come after a respiratory arrest, rumbled in my head. For a few moments, I had the wish that everything would end there.

There had been too many shocks before this one, which I can consider as the most unfortunate of all. While the doctors were with Carlos in the emergency room, we called our relatives.

The doctors came out to tell us that the baby was already stable and they let us see him. Carlos cried of hunger, it seemed that nothing had happened. The doctor who had sedated him disappeared from the hospital and appeared until seven o'clock at night, thanks to the pressure of my father-in-law, through his acquaintances, so he would explain to us and avoid a lawsuit. His justifications were useless; the damage was done.

That day his smile vanished, the awareness of the world around him, the visual contact that we had, his scare reflex, his muscle tone and a more encouraging future than the one that awaited him from that moment. His mind traveled to another galaxy, and only very sporadically did he come down to give me the courage to keep fighting and bring him back. A part of me went with him. I disconnected myself from all desire and personal projects to dedicate myself to his rehabilitation and to my other son.

My life took a turn. To feel that I had everything in my hands when Ray was born, with Carlos I felt as the most defenseless human being before that life and that destiny that depends on me to date without being mine. Were months of asking myself the same

questions: why him? why me? And with all those questions, I searched for the moment when I did such a tremendous wicked thing that I deserved that punishment.

Many months I cried without finding an answer and I lived bombed by uncertainty, disappointment, dread, pain, rage and sadness, until I found relief even without having an explanation for what seems to me an injustice, not for me, but for the life of my son.

It hurt me to think that he could never go to a school, that he would not have friends, that he could never have a sexual relationship, a couple, a family. I quarreled with God everyday, I cursed him countless times, although later I regretted it, but with the same speed returned the questions about the compassionate, benevolent and fair God in whom I believed a great part of my life.

The situation was hard to accept because of the future that was expected after this event; fortunately, Carlos stayed with me and I did not lose the great opportunity to have and be what I am now. Since that moment I stopped thinking about tomorrow, I dedicated myself to live in the present and to avoid remembering the day before.

I cried for almost a year, each and every one of its days, before going to sleep, when I woke up, on the way to work, back home, when I was going to have my period, when it was over, when I had two seconds

unoccupied, on Sundays, on Tuesdays, every day. There were moments when I wanted to run away and scream until tearing my throat, pull my hair, insult God, the Church and everything in what I thought that was fair.

Some time later, in my urgent need to understand and explain to myself everything that was being reflected in the development of Carlos, I decided to talk to the pediatrician that received Carlos, to ask him about the details of the birth, and until that day he explained to me what had happened in the moment of delivery, the hypoxia and everything that entailed a brain injury.

I only confirmed what I already knew as a result of the postpartum events. No one mentioned to me the possibility of seizures. That same day, the doctor told me about it and about the learning problems. I have the vivid memory of my feeling in that and many other moments of this entire trip.

I left the doctor's office confused and really hit by the news of the seizures that came to add to the neurological delay, the spots on the skin, the lack of reflexes, , the changes in temperature of his body and his excessive head, as well as some physical characteristics that began to be evident, such as small bags under his eyes and the shape of the joints of his wrists, which made him look disproportionate. There was also the lack of erections, his very short periods of

sleep during the day, the repetitive hitting by himself in his stomach as if he was hitting a drum, his desperate crying when there was a lot of noise, and my anxiety and anguish that I radiated the twenty-four hours of the day.

I came home to cry full of uncertainty. The only thing that gave me moments of peace was his smile and the visual contact that we had from time to time.

For a long time, my husband and I lived covered by a gray fog and by the silence of the spirits of our consciences. Everything was very painful; we went to children's parties and we saw all the children running, smiling, playing, while Carlitos remained seated, like a defenseless little plant, with his eyes on the sky.

My husband and I did not say anything to each other, but the next day our eyes had the brightness of the contained tears, the corners of our mouths withheld the crying and reflected despair. Sometimes we cried together; they were few. I guess that we wanted to show strength to each other. I know that he cried many times alone, and that he lived his process relatively alone. I cried with my sisters, secretly, and also when I hugged Carlitos.

One week after the respiratory arrest, we started with rehabilitation therapies. I do not even remember who recommended me to the first therapist with whom we worked with. We went for an hour everyday and I repeated the therapy at home twice a day. The

respiratory problems were constant and, unfortunately, I put again the health of my son in the hands of another doctor who prescribed antibiotics indiscriminately, and that I, in my damn ignorance, administered to him. He never gave me a treatment to take care of his intestines, which were already injured before and we did not know it.

I have always been a very organized person, and since my children were born, I took care of keeping all the prescriptions and medical studies of both of them. The well-being that has always given me writing my emotional states in diaries, was also very useful for me in this situation, since I began to write not only how I was, how I saw him, my wishes that everything would improve or that it would not get worse, but also how he woke up, what he did, if at any time our eyes made contact, if he tried to grab an object (he was already seven months old and he still did not hold anything in his hands), if he laughed, moved, if his head was hot, if he pooped or not, how many hours he slept, at what time he woke up, how much milk he drank, the times we did the therapy with the therapist and at home, the reactions he had to the stimuli, everything, whatever that I wanted to know was in that notebook.

I spent more time inventing things to stimulate him, and his dad getting everything that I asked him so that Carlitos would get better. I lived for him. This had its consequences with Ray, my other little son.

I must say that my suffering at the beginning, when the rehabilitation began its way, went from the situation of Carlos, to the loneliness and lack of time and patience for Ray and what he did. As a little boy, I suppose he felt totally displaced by his brother who occupied all the time of mom. In addition, people who came into our lives at from that moment on, such as nannies and therapy assistants, were attending Carlos all day. That killed me, because he began to act sullen, he cried for everything, he was rude to those who helped us and from school I received reports that he would go under the tables to cry and he was distracted. All this tortured me for many years and, in some way, it still tortures me. I never wanted him, the light of my eyes, to suffer. That child that made me go crazy with love, that still makes me fall apart and will always do. He is my light, my oxygen.

In spite of everything that I was told about the time that I should dedicate to Carlos and Ray, I never accepted that fact of not worrying about the older one because he would understand when he grew up. That idea, up to date, fills me with rage. The times that I heard it, I thought that neither of them was responsible for the situation of the other, that they were both my children and that I would divide myself as equally as possible between them. Carlos was going to get where he had to get without implying further harm to Ray's welfare. I did not want him to hate his brother. This



dilemma coincided with the visit to one of many doctors, and in the consultation he told me part of his personal history. He had a brother with a similar condition, and he told me that he could never overcome that his parents had dedicated their body and soul to his brother, because he was very lonely and, until that day, he felt a lot of anger against his parents, his brother and the situation.

At that time, I totally confirmed that my two children were equally important to me, regardless of the conditions in particular of each one. This situation was a huge challenge for me, something as hard and painful as Carlos's circumstances. I always tried to explain to Ray the situation of his brother up to where I thought that he could understand. Remembering this drowns me in pain, but that is another story.

During the first months of therapy, and after being with neurologists, geneticists and dermatologists from the Social Security, we were confirmed the diagnosis of Hypomelanosis Syndrome of Ito. Just to be sure and without doubts and to finish to confirm, we went to the Children's Hospital of Mexico City.

Each trip away from home was a painful and extremely tiring adventure. Queuing from the dawn, the anguish of what we would hear, the pain of what we would see. Until a few years ago, I was able to find a phrase that would give meaning to many of the things that I had lived and thought before and

following the birth of Carlos: one can only see what one knows. Many things went through my eyes for years regarding families, individuals or life circumstances related to children with some type of brain injury and I never saw them. Today they are very evident to me, and they are only because I live in one of them.

There were also trips for Carlos to receive therapy. I used to go alone with him to these ones, since he was still manageable because he was a baby. I was still at a stage where I lamented everything and lived in doubt whether the God in whom I had believed all my life was somewhere.

I ended up getting away from religion during a stay in Mexico City, in one of the many trips to receive therapy. On that occasion, I accompanied my aunt, who introduced me to the father who was at the head of the church in my neighborhood when I lived there. The only thing that I remember from that talk is that he told me that my son had been born in those conditions because I did not do it with love. When I think about that, a buzzer comes immediately to my head that marks the mental block that came after I heard that comment. I do not remember anymore.

At night, while I cried and my aunt repeated to me that my son “sick” was God’s will and that I should thank him, I told him what his friend the Father had told me. There was an absolute silence; she could not

say anything to me anymore. I never went back to church again.

My peace of mind today lies in my relationship with others, with Carlos's situation, with what I have of him and of life itself; until today, I do not need God. As Wittgenstein said: "God is a feeling", and I absolutely agree. So far, God or life itself continues to fill me with wonderful things.

Among all that we tried to improve his attention, was the Tomatis method, which cost a fortune but we decided to try. This method is auditory and uses filtered music. I saw immediate changes in Carlos. I remember that they offered to play some music to help me relax, which I accepted immediately because I felt very bad. I could only bear it for ten minutes because what happened in my brain was that it created a horrible sensation of anguish and sadness. I cried non-stop for many hours after I left there, until the effect passed. I did not accept it again.

During the search for other alternatives, when the stimulation that Carlos was receiving began to be insufficient, a book about how to help children with brain injury came into my hands. Reading it filled me with hope to help my son, but it also provoked a moral struggle between my desire to cure him and having to put aside my life and professional development.

I remembered that one day I went out with my husband to the bookstore, he found the book and we

bought it. He read it first and told me very excited that I should read it. When I was in the middle, while my head was thinking at the speed of the light, my heart also was being knotted.

In the first thing that I thought, after all the encouraging that was the book for the life of Carlos, was in my personal life, in everything that I would have to continue doing aside, since the proposal involved working around the clock, mainly me.

The struggle began between the things in which I believed and the overwhelming social discourse. Who else if not the mother? The instinct is what it says! The book described a treatment in which, in a way apparently simply, the mother had to not only make her life aside to work with the child twenty-four hours a day, but mediate with the rest of the children and the husband to make from the treatment a means of happy life of the whole family.

Finally, as I wanted the best for my son, I decided to take a break without a time limit. The four of us locked up for five years. My husband and I faced all kinds of remoteness and blame for not responding to all the mutual demands and to all that my other son made.

I closed my gym and started this method of rehabilitation in a hidden place, where during my first visit I felt losing the rest of sanity that I had left. I thought that it was the dirtiest and saddest place I had

ever been. Sitting on the floor with their respective mothers were about fifteen children, the majority of them motionless, each one of them as fucked up as the other. The saddest thing was not to see so many children in that situation, but to know that this place was the only option for them; all of them were of very scarce resources.

Getting here was a tremendously hard experience, but the one that has enriched my spirit the most. If my son's case seemed to me tragic, the circumstances of these children showed me that I was wrong. Each experience with them came as a slap and I discovered how valuable is a single inhalation, a blink or the movement of a finger.

The method of rehabilitation that the wonderful woman who accepted me in this place applied, as she understood, was the one described in the book that I found with my husband, the Philadelphia Method. Even with all the shortcomings about the real work of this program in that place, my son had many advances. He started it here, but at the same time I investigated the requirements to carry out the method formally. I must admit that the more that I became involved, a pain embraced any idea of a personal life.

Loreto is the name of the woman who ran this place, sponsored by a patronage of women with money, some, mothers of children with an injury. It

was a two-storey house adapted with materials and devices that were required to carry out the method.

I arrived there every day at eight in the morning after leaving Ray in kindergarten. On the way, I used to sing to Carlos the songs that made him smile; I needed to fill up from the energy that his smile gave me.

The first months were terribly hard. Arriving and seeing everyone's conditions was extremely painful to me, not just our situation. Carlos cried from the time we arrived until we returned at four o'clock in the afternoon to our home, where we continued working with some parts of the program that required to be repeated tirelessly.

At first I blocked my heart and my senses to endure what hit me from that place where I started with the therapy and the pain caused by the endless crying of my son, but when I got home I cried inconsolably until I felt that I was taking off tons of weight.

My husband went in the morning when he could, not to see how Carlos progressed, but to make sure that I was not going crazy. Time after we started working at home and that he saw me more calmly, he told me that when we were still working in that place, I looked really bad. I know that I lost my smile for a long time, but everything ends up adjusting.

The conditions of the place were very poor: there were not enough fans for so many people, the floor where the children crawled had no protection, the mothers and their children sat in the assigned corner with their bags of clothes, diapers and others. Little by little I made of this space almost my second home and I went from feeling sorry for everything and everyone, to deeply value the well-being that all this gave us to those who spent a great part of the day there. I do not know at what point I began to feel more relaxed and to transmit joy and hope, I suppose that when the advances of Carlos were visible.

To enter the program of the Institutes for the Development of Human Potential, located in the city of Philadelphia, United States, from where the method in which I was working comes, requires to fulfill a series of requirements by both parents of the child with brain injury. First, it was to read the book and to having started a home program based on the explanation given in it. The second step was to take a course exclusively for parents which is given every so often in Philadelphia and only once a year in Mexico City, for which we had to wait. There, a tutor was assigned to us, who would receive by mail and by telephone all the information of what was done at home and of the progress, data that would be the pass to be accepted in the intensive program. What is evaluated in this information is the perseverance of the

parents, measured with the hours dedicated to the method.

We had to work all day. When waking up, Carlos had to start with the program of the masks: a plastic bag adapted with an elastic in its opening, and a tiny tube at one end where oxygen is allowed to enter, since the bag is placed in the face of the child, covering nose and mouth, with no air entering otherwise than through the orifice of the tube. The mask should remain at the beginning for one minute after the child's breathing starts to accelerate. All this process has a logical and scientific explanation.

This part of the program is one of the fundamental steps. The difficult thing for me was trying to get used to the face of despair of Carlos to the urgency of oxygen as it came the minute to take it off, to hold his hands so he would not tear it away in his anguish of feeling his suffocation.

When I think of this, it seems that I am the one who is wearing the mask, I feel my breath shortening. I can say that this saved his life in many ways, but I was traumatized by the timer that rang every five minutes in the day, to do the one-minute mask exercise, and so on as long as he was awake, even at meal time. Every day, we repeated this action sixty times at least. Between mask and mask, we made the crossed patterns of movement in a special table fourteen times a day, each of these for another five minutes with an interval



of around fifteen and twenty minutes. In those intervals, Carlos had to read the material that I did for the reading program, crawl chest to earth for four hundred meters divided into parts, crawl one thousand and six hundred meters, walk for five kilometers and a series of other things. This was when the program was in the most active part. It is a process that is on the increase, and as things are achieved, the activities decrease and are replaced by new ones to develop other skills.

Before starting intensively, we had to wait for nine months to receive by mail the invitation to join the group. The letter arrived one day in July, almost two years waiting for it, and we had to be at the Institutes on September 23, 2001. The trip staggered for a few days because of the attack in New York, but even with all the restrictions that were taking place at the airports and the fear that something else could happen, we went.

To carry out this therapy at home, I had to hire two people whom I trained little by little and, who worked with us from Monday to Friday and, who had to alternate working for Saturdays and Sundays from seven in the morning to seven in the evening. We also hired two other people to take care of my house, for cleaning and cooking, as well as for being Ray's nannies.

We made a beautiful team. I am sure that the four of them did not come by chance, they worshipped my children and dedicated themselves in body and soul to their work. Rosi was with me for ten years in therapy, as Alberto; Sara has been with me since Ray was born, so she has been seventeen years living at home, and Ana has already twelve years cooking deliciously for everyone. They are part of my family.

Nothing stopped me. Even after hurricane Isidoro in 2002, without water and without light for more than eight days, we worked at home without stopping. We did the five-kilometer walks with obstacles, since the parks were devastated.

On that occasion, during our biannual visit to the Institutes, Carlos obtained three victories: stand up independently and stay standing up; in walking, to reach the five kilometers, and in the reading program, to have a certain number of words learned and in their level of understanding.

We obtained a special recognition from the deans, since on the fifty years of operation of the Institute, Carlos was the second child who had so many achievements in six months, despite all the climatic difficulties that could have delayed the work. We all returned home very happy and with greater enthusiasm to continue working.

For five years we traveled to Philadelphia every six months; a month before, I would loose pounds of

weight due to pressure and I had neck and back contractures. the pressures were many: achieve the goals from the program, select much of the material that had been read in six months to take as evidence, prepare the huge suitcases to be there for ten days, arrange with the family to leave Ray with them when he did not accompany us (he went with us once a year), make a list of his activities so his grandmother could take him, prepare a day before, all the special meals for Carlos for his transfer, put them in special refrigerators to be preserved, to pack medicines, ask for prescriptions to be able to pass the Valium through the customs in the event that he had a seizure on the plane, and, we had to be very careful with his health fifteen days before so that he would not get sick.

The journey was stressful. I worried in advance that it could be uncomfortable when he wanted to sleep, which he did on my legs and on his dad's, when we still did not have to pay a seat for him, asking the flight attendants to heat his food, when he pooped the diaper and having to walk to the tiny bathrooms to change the diaper. Every six months thing were more difficult because he was bigger.

Already in Philadelphia, we had to go to the supermarket and prepare his meals at night for the stay, which sometimes was for more than ten hours, at the Institute. The stress of waiting was enormous, since the appointments are by groups of children,

approximately of twenty, with their parents or relatives who were involved in the therapy.

Wait for your turn, show your achievements, take a series of lectures while they are still working there with the children, since the place is conditioned so as not to waste time and so they can crawl, walk, do lots of exercises with the masks, read and more. The nice part was to see all the families from different parts of the world, to talk and share the achievements of our children. The people of the Institute were always very kind to everyone.

Returning home, we would arrive on Saturday night more tired than we were when we had left, picking up Ray, unpacking, going to the supermarket the next morning because there was nothing to eat, and then start to wash tons of dirty laundry.

The time off was only on Monday, when the nannies and the therapy assistants arrived to take care of Carlos, while I tried to sleep for a few more hours. On Tuesdays everything would start again. I avoided thinking, my mind was on pause.

What saved my life when facing all this stress during the years that we traveled, was that I got up from Monday to Sunday at four in the morning to run twelve kilometers from Monday to Friday, Saturday eight and Sundays eighteen. Those were the sixty or ninety minutes when my body was disconnected and my head could think in something else: to finish

running those miles day by day. In seven years, I did not get sick, not even a cold; there was no time to lose. I returned home at six o'clock in the morning, already relaxed, to prepare breakfast for Ray, leave him at school at eight o'clock, return to do therapy and material for it.

At ten o'clock at night, I just put my head on the pillow and lost consciousness, each and every one of these hard days. I quit parties, friends, many of the reunions with my family and I forgot about myself and everything that I aspired to be.

Many times I wanted to get sick and be in a hospital bed attended by many nurses; that would be the excuse to rest without feeling guilty of wasting time. My life was: running, therapy and to take care of Ray as I could.

Carlos, in all these years and with this method, achieved many things. When we started, he had no fright reflex, a bomb could explode at his side and he did not flinch; ; his pupils did not expand with light; he lived with ragged breathing, since he did not have a breathing pattern; he did not have the prehensile reflex, Babinski's; there was no sensitivity in his skin in most of his body, but in others, such as the hands, head and mouth, he was hypersensitive.

With this method he managed to grab his bottle, sit down, put himself in prone position, slither, crawl, get up off the floor and walk, walk with intention, go

willingly somewhere. Run ten meters holding hands, execute some jumps with help. Eat assisted.

I must admit that I had a hard time convincing myself that the reading program was working. It was a part of the method in which he did not show much interest. It was rare the time when he fixed his eyes on the material, I had to look for his sight; nevertheless, in one of the trips, the person who examined that part of the program was the one who asked Carlos about what I had read him a few minutes before, and to whom he answered very clearly. I was really surprised. I must clarify that when children do not speak, as is the case with Carlos, everything is visual. The questions are written and they only touch the answers when they have mobility and coordination, or they simply look at the answer when they do not have it. My son answered when he felt like it by touching and, sometimes, he just looked at it.

One of the many ways to survive this, was also the way how I accommodated my desires about his achievements. I never thought of my desire of him walking when he could not even hold the bottle. Once he held it, my mind moved on to the next wish, which consisted that he would hold himself seated; then, that he would sit by himself, and so on, step by step.

We managed to recover his reflexes; however, the disorder in the sensitivity of his body still remains. He lives with the anxiety of biting hard things, until his

gums bleed, in rare occasions he lets me stroke his hair.

The method also covers the feeding part. Who would say that the year that I studied nutrition and everything that I learned by myself when I had my gym would be so useful to me. I made his diets counting calories, and in the particular case of Carlos, this part was even more delicate, since the results of the intestinal damage caused by the antibiotics that he took for so long had manifested. It was a diet very limited in variety, nothing with gluten, preservatives, dyes, nor sausages, cold meats, beef, pork, dairy, sugar nor salt.

Despite all these cares, the problem of the intestines began to worsen with diarrhea and his intolerance to all that food.

Over the months I could see that the seizures were directly related to what he ate. They started very lightly, sometimes almost imperceptible at the moment, since afterwards he fell asleep and was hypersensitive to the sound, and his state of alert improved in an impressive way. The bad thing is that he did not sleep at night anymore and all the therapy work was starting to get complicated. The time came when they became so severe that we had no choice but to resort to anticonvulsants, against the will not only of my husband and mine, but of the Institutes, since one of the objectives is to ensure that the children

overcome them without medication or with the least of them when there is not other choice but to use them.

This part of the story was extremely exhausting, and the trigger for everything that had resisted my sanity. I tried not to cry when I saw my son shake, or fall to the floor from the chair, or wake up when he felt that his little body was jumping uncontrollably, seeing his eyes fully open looking at nothing and his pupils fully dilated. I gave him slaps, pinched him, put ice on his chest, masks, I called him out loud saying his name, assuring him that nothing bad was happening, that I was there, next to him. I saw the face with tears of anguish of my other son when it was his turn to watch them, I waited for eternal minutes for the seizure to end, and then caress him and watch over his immediate dream, or move him to his bed when he could not hold on to one side of his body.

I already knew that after this would come the bad night, since he could not sleep because of the auditory hypersensitivity resulting from the seizure. I waited, for the sleepless night, with a knot in the pit of my stomach and pleading to life that we could all sleep because we were exhausted at the end of the day.

After a convulsive crisis, he stayed disturbed, to such an extent that, when we went to bed, I tried to have absolute silence, but even my breathing made him jump and wake up; to fall asleep could lead us to stay awake until six or seven in the morning.



Sometimes he did not want to lie down, he screamed and hit the doors or windows. I, in those hours, could not contain the tears of despair and rage that spurted down my face, because all I wanted at that moment was to sleep.

The next day was a lost day for therapy. How terrible! How did I endure? I do not know. There were days when I exploded and cried aloud until I got out all my pain, despair, rage and sadness.

The convulsions became the enemies of work, they became recurrent and after, he would become very disorganized neurologically. I felt a lot of pressure every time that the next trip approached, because the work started falling behind. In addition, he began to lose the few words that he managed to articulate and that made me very sad.

Starting to use anticonvulsants was very unpleasant, as he complained all day, he pinched us and pushed us, since he did not tolerate having anyone nearby. The difficulty of this part was to reach the ideal dose, in addition, to get the right medication, since, in his case, not all of them were good for him and we had to start all over again. We gradually removed the previous one and went through a period of fifteen days of symptoms until we were able to stabilize him. There were days when he had up to eight convulsions of more than two minutes; I thought I was dying of despair. I did not feel in the mood or

with the security of leaving him alone for a minute because of the fear that the crisis would come to him when he was standing and hit his head. Emotionally I started to get very sick and to feel worn out. For my reason began to haunt the idea of taking a break, at least to control the diet and, of course, the seizures.

After seven years I decided that we needed a vacation. Carlos did not want to do anything anymore. The therapy that most of the time had been full of enthusiasm, became a therapy full of crying, cramps, convulsions, bad night and reluctance. I felt morally weakening every two steps, Ray demanded attention and my husband became gray-haired as result of worrying about my emotional state, the health of Carlos, and the money. I had the idea of suspending it only for a few months because of the fear of losing what he had gained and not achieving what was still missing. I wrote a letter to his tutor explaining the situation and he told us to take as much time as necessary. After two months, I did not want to know anymore about the method. I was dead, I felt empty.

The struggle to achieve the semi-annual goals of the method was replaced by the fight against the seizures and recurrent colic. I started by removing some foods, I lived for months searching in the internet, in different groups of parents like us, exchanging tips and sharing sadness.

In order to not feel guilty about not wanting to return to the therapy that we had taken, I did what gave me a bit of tranquility and looked for other options of work that were more relaxed and in which he could be calm. So, I agreed with a mom who recommended me to a doctor who was in Monterrey and who could help me with the problem of the intestines.

We made the appointment and once again we undertook one of those hard trips, so stressful because of the food. The explanation that he gave us about the diet that we would have to begin sounded logical to me at that moment, and in my desperation I would have accepted anything.

Carlos began to eat only and exclusively chicken meat boiled with salt and all the skin; his drink was water. His meals were four times a day, 350 grams of meat already cooked and ground. In the beginning, it was not difficult, because he did not ask for more. The cramps stopped, those which had taken us to the hospital many times, in which he wallowed in pain and we did not know what was hurting him. They were terrible moments. We learned to distinguish with his crying and his discomfort when it was a colic and when it was a headache.

After a month and a half, his muscle mass had increased impressively, he was taller, the seizures decreased, but the spots on the skin were very

noticeable, since there was a huge vitamin deficiency and he did not tolerate any supplement. All the doctor asked me for were vitamins that I had to order from the United States, and they ended up in the trash because, when administered to him, the convulsions came one after another. He slept half the day and that anguished me, he did not want to walk in the park anymore, his life became more sedentary day by day. I started to despair, and started thinking if one day he could eat more things again. Emotionally, I was very bad. I cried very often out of sadness.

Back then, when I told a doctor about the diet, his comments were offensive, he told me that how could I deprive my son of everything else. Usually I am very prudent when I am offended, but this time I replied that, fortunately, his children were healthy and did not have to be moving heaven and earth for their health. Once again I thought about how the doctors become monsters when they believe that everything in the books that they study is what exists. I was with my son twenty-four hours a day and I knew every one of his reactions that went out of his “normality”. I did not have to learn it by studying medicine, life rubbed it in my face at every instant.

Carlos spent eleven months eating only chicken, until the circumstances put me on the road another family that recommended to me a new doctor from Ciudad del Carmen. I contacted him and we went to

see him; I owe this man my peace of mind. The first thing that he recommended were some vitamins, that cost twenty-five pesos, that did great to him, and from there we started.

The day that I arrived for the first time at his office, I told him that I was putting the life of my son totally in his hands, that I was defeated. Today, the only thing that Carlos does not tolerate is gluten, and even like that, he can eat cake on his birthday, since two ago, and after not having done it for twelve years.

At some point it was a dilemma, a moral conflict product of everything that we learn about how things should be, to choose the birthday or Christmas gift. Thinking in a toy that he would like or in something that would really catch his attention, was very difficult for us. Now I have solved it by buying to him things that he needs, and for him to play, we know that he loves wooden drums. His paternal grandmother is the one who has given them to him in recent years.

Having a limited child in many essential functions for his independence and survival can be frustrating at first, not only as a mother who wants “whole and healthy” children, but as a woman tormented by the “moral” duty of having to make her own life aside to feel “normal” in the eyes of God and of the rest of the mortals.

For me, this represents one of the incomprehensible moves of life, and rather than

considering it a punishment or a lesson, it is something that has helped me to be a better person with others and has given me a professional opportunity, because without asking for, I got involved in things that I like and that opened up for me possibilities not previously contemplated, by allowing me to think again about plans and projects that even if they are very different from those that I had in mind ten years ago, I have them in my hands and they fill my spirit completely. The moment came long before than expected, to think again about me and my personal life.

At the beginning of this situation, when I decided to make a pause without time limit in my life, I never stopped to think about what it would mean over the years. I realized this, when I suspended the therapy and I remained without doing more than the role of mom and housewife. The days on which every minute was so valuable and so short, turned into eternal minutes. When I quit the therapy, I slept about two weeks in a row, I woke up early, went out to exercise, I returned to bathe and have breakfast, I felt tiredness coming and I lay down to sleep again for more hours during the day.

As the weeks passed, when my body felt more rested, it was when I felt the emptiness. I repeated to myself that I needed to resume my life because the role of a housewife, and nothing else, was not my thing. So, when I became aware of time, I began to think about

how I could take advantage of what I had learned, since apparently it was my only experience.

The age at which, I suppose, one acquires work experience after studying a career, was the time that I devoted to therapy with my son. So, before falling into frustration, I preferred to look for the “advantages” that, to a certain extent, the apparently bad things of this whole stage of my life could have, and this attitude has helped me feel satisfied in many aspects of the traditional roles that I perform as a woman and as a human being. It was then, that I began to see things that I had not contemplated for my personal future, like all the knowledge acquired in terms of the development of the human brain and its rehabilitation.

However, other types of feelings have also invaded me for moments throughout this trip: sadness, when I think that, despite everything that has been done, we have not been able to hear the voice of Carlos saying at least one continuous phrase. It would be great to know the tone of his voice, that melody when a child articulates several words to express himself. Every day is closer, the painful idea of his dependence even in his most basic needs, such as eating; I only wish that when the time comes for him to leave, that he leaves before me so that he never lacks what only his mother can give him, or that we both leave together. What struck me the most, was when his brother asked me hopeful if Carlos would be cured. I tried to find a subtle way of

saying to him that each day the possibility that we wanted so much was further away.

Today Ray, already seventeen years old, after innumerable talks, he knows what are the causes of his brother's injury and that his condition is likely to remain very limited. We have cried together; nevertheless, I know that he is still in the process of understanding the situation, facing the perception of the people and the cruel way of expressing about people like his little brother, to whom he loves and whom he includes in part of his life plans.

I know that Ray wished for a long time to be able to play with his brother, but it could never be the way he wanted. Their relationship is based on kisses and cuddles that they give to each other, more on the side of Ray than of Carlos himself.

We have talked and he has told me that he never felt anger towards his brother, but towards all those who were close to him, but that he has overcome the test. He loves Carlos, he helps him, he bathes him, he takes care of him and he has been a child who always talks about his brother with a lot of pride before people. The only thing that he does not tolerate is discrimination against anyone in situations similar to his. This gives me great peace of mind because I believe that, in spite of all the suffering and guilt that I carried for years regarding my time with Ray, he values all my efforts.



In the new search of my person, of my plans, I thought about starting a medical career, or rehabilitation, possibly psychology. I evaluated the options and, in that lapse, one of my sisters, a psychologist, with whom infinity of times I arrived exhausted in tears, suggested the possibility that I could study a master's degree in psychotherapy without having to study a career in psychology, since my credits of the certification that I received in Philadelphia in Rehabilitation and Development of the Human Brain, could be the pass to allow me to study the master's degree. So it was.

Entering the master's degree was the best decision in my professional life, and it has been a turning point.

Trying to see life in a different way and accepting that things are like that, as they arrived, and that despite of all my attempts, and those of many others, in some things we were far from reaching what could make us feel better about the life of Carlos, has not been an easy task.

Carlos still does not speak, I mean, he does not articulate words, he only babbles. The hearing hypersensitivity goes up and down every day, sometimes while he is awake, and up to an hour after having fallen asleep, he is with the shells in the ears to block the noise. He has no background perception, his body temperature changes are very frequent, his extremities get very cold, and when he is like that, he

screams and it is necessary to put the shells on his ears. In a few minutes his temperature returns to normal.

Sometimes the light from the spotlights hurts him. Once in a while, his breathing shortens, especially when there is a lot of humidity in the environment. In five years he has only had one seizure. There are days when he just wants to lie down. All this is part of his normality. I no longer despair as much as before; however, it still distresses me. Neither do I try to find explanations for everything.

I do not know when, perhaps today, as I write, I will be realizing that accepting what it is, as it is and as it arrives, has given me great peace, it has allowed me to feel strong and free. This experience has prepared me for many other things. I am not afraid and this allows me to live and enjoy everything I have, to live intensely every event in my life. The pain does not dissolve, it stays there, in the memories, but today, and I do not know if tomorrow, I can afford to bring them when I want and to use them as a way to get rid of so much weight. The meaning of life is not found; it is built.

I am still in the fight every day. Sometimes I feel falter when things move away or get more difficult than I expect, but there is always a look or a spontaneous and pure smile from Carlos to raise my spirits again. I have always been convinced that I love living; I love life despite its bad moves, which have

compensated surrounding me with exceptional people and who have been like pillows over stones in this exhausting road.

Many times I would like to see the things that only the eyes of Carlos look at, to enter the world in which he lives and of which I can only suppose that it is a place full of light, warmth and peace. I wish one day he could tell me what he sees and hears; I see him so happy that I envy the happiness he enjoys.

At some point in all these years I thought that I would have given anything as long as Carlos could enjoy the things of life as I do; nevertheless, I am not so convinced about it anymore. Life is as it happens when the events are out of our hands, of our decisions.

During all the years of therapy there were moments when I felt totally exhausted physically and emotionally, without wanting to do a thing. For years, I was trying to lift that apparent curtain that prevented us from communicating verbally; still, it is almost impossible for me to know how he feels. At first, his lost look seemed to be far from the feeling, but as he looked at me, that empty box started to fill up, the one that, I suppose, did not even distinguish what was all that pleasant warmth with which it was stuffed. The only answer that something about me was pleasing to him, was watching him fall asleep or calm down when hearing my voice singing a song to him. In fact, everything that implies the meaning of life for Carlos,

are only my assumptions, to which I have attached myself, to give meaning to my pain.

Now, even without telling it to me with words, I know that despite everything, we have always been communicating, I can feel that he loves me, his gaze tells me everything. Before, I had the desperate need to hear his voice saying any thing, now I am content with whatever he can give me. There was a period in which he was able to articulate a few words that came surprisingly, this was music to my ears, that hoarse voice, sweetly hoarse. Unfortunately, when the seizures stage arrived, those words vanished.

Many times life ached me, Carlos ached me.  
Many times I felt satisfied and at peace.

I also went through periods in which my willpower, my courage, my tranquility and hope, tottered. Sometimes I lost that strong attitude towards life, I felt with little energy and without wanting even to think. I just wanted to run away, or sleep and wake up to see that everything was as before; it was the despair of not having an answer to many things about the health of Carlos, and it would have been so different if I had found an explanation, even if it was not in my hands to solve it, those days the only thing I wanted was for everyone to leave me alone with my soul.

In the last six years, I have run into people who question me why my son is not having any kind of help. At first it caused me not only discomfort but also guilt. Today I feel that I do not have to give explanations to anyone about the decisions that my husband and I have taken about the life of Carlos.

We have accommodated our existences; I also have the right to a life. When we quit the therapy, we took him to one or two places, but it made me sad that they were spaces where he could only be with people like him. When I asked for permission so he could go with his shadow to the school where his brother was going, I was replied with a resounding no.

After I have freed myself from guilt, I feel more at ease that he is at home, being cared by people of my absolute confidence, more when I was able to develop professionally, I have a job in a university as a psychotherapist and I give consultations in the afternoons. He is at home with his nannies; in the afternoons we go to the park, Carlos is a fourteen years old, bearded man, 1.70 meters tall. Even without therapies, his neurological condition improves little by little, as does his balance and attention. He expresses love, he kisses and he smiles most of the time. He says mom and dad.

I have done to this day absolutely everything that has been in my hands for the health and life of Carlos. I do not worry anymore that he is not going to school,

that he does not have friends, that he acts at his fourteen years like a child enslaved in three; that at eight he had entered into puberty or that he will never enjoy a relationship of friendship or as a couple.

The only thing that I want is to feel that he is happy – inside my conception of happiness –, surrounded by love as up to this day, and to please him in the few things I suppose that he enjoys, like going for a drive or sleeping in a hammock and waking up every day of his life in front of his mother, his father and his brother while we fill him with kisses and cuddles.

If the conditions of Carlos at birth had been as expected, I do not know what I would be writing. Possibly my life would have been less intense and perhaps there would not be the need to write about it, the end would be about the perception of me and the relation with everything around me. In reality, my story will always be accompanied by Carlos, because every thought, decision, act, desire or dream that I have revolves around him, every second of our lives. We will always be holding hands.

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