



THREE CHEERS FOR THE BABY!

GUIDE FOR MOTHERS AND FATHERS OF CHILDREN WITH
TRISOMY 21 (DOWN SYNDROME)

MOVIMENTO DOWN SERIES

THREE CHEERS FOR THE BABY!

GUIDE FOR MOTHERS AND FATHERS OF CHILDREN WITH
TRISOMY 21 (DOWN SYNDROME)

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E MOVIMENTO DE AÇÃO E INOVAÇÃO SOCIAL

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PRESENTATION



THREE CHEERS FOR BABY!

This booklet was prepared by mothers and fathers who, like you, have had a baby with trisomy 21 or Down syndrome. Many of us received the news in an inappropriate way, with a negative attitude and outdated information. So we want to share with you what we felt and say what we would have liked to have heard at that time. The first moments were difficult, but over time we learned that our children are just like any other children, with a promising future ahead. And we saw that their birth brought many joys to the family.

Congratulations for your baby!

Movimento Down

ABOUT MOVIMENTO DOWN

Access to information makes all the difference in the life of a person with trisomy 21 (Down syndrome) and her or his family since birth. With up-to-date, high-quality information you will understand that, like anyone, people born with trisomy 21 come to the world full of potential. Movimento Down was created to bring together free of charge content for people with trisomy 21, their families, professionals and the public in general, that contributes to their development and promotes inclusion in all areas of society.

Nowadays there are examples of people with trisomy 21 and intellectual disabilities in many countries who are achieving important goals such as studying in regular schools, reaching higher education, working, participating in their community, living by themselves, getting married, advocating and fulfilling their rights. Their confidence to break down barriers is directly linked to their families and those around them, who believe in their capacity.

Our network of partners is key to turning so many projects into reality. Movimento Down has the support of companies, Government and non-governmental organizations, and the participation professionals from different areas, activists, family members and people with trisomy 21. You are also part of this network.

Help spread the word Movimento Down, our publications and projects.

Together, we can do more!



THREE CHEERS FOR THE BABY!

“ Your son is just like any other baby in the maternity ward, he just may take a little more time to learn things, but with all your love, affection and encouragement he will surely be able to do everything in this life. ”

Congratulations on the birth, or the baby that is to be born!

Although you may have been surprised to learn that your daughter or son has trisomy 21, we know from experience that, with time, she/he will be a great joy for your family.

Most parents find that their baby has Down syndrome shortly after birth and usually the news is perceived as scary. We understand that your life took an unexpected turn, but we want you to know that you are not alone and we hope to help you celebrate the life of your baby.

“The lack of information is the worst thing at this time, because the anguish caused by the unknown raises unnecessary fears”

BABY IN THE WOMB

Maybe you have found out, through prenatal screening test, that your child is likely to have a diagnosis of trisomy 21. This booklet will answer a lot of your questions and help you prepare for the future.



BREAKING THE NEWS

The birth of a child is a time of tension and excitement for parents. Because of the hormonal imbalance they go through, new mothers may have conflicting feelings and sometimes may experience postpartum depression, also known as baby blues. It is not surprising that, in this vulnerable state, the news that the baby has trisomy 21 causes a shock.

DO NOT HIDE YOUR FEELINGS

People react differently. Some may feel sadness or a strong sense of overprotection towards the baby. They may also feel ashamed or as if they are numb, unable to react to what is happening.

Feelings of rejection to the new baby may also occur. This is natural. Most people feel that way and later realize that they have not rejected the child, but the disability.

EACH ONE REACTS DIFFERENTLY

Do not assume that your partner is not feeling this moment the same as you. Each person reacts in a different way. So, you two should talk openly about it. Also talk about your feelings with professionals or close friends. It is a great way to vent. At the beginning, bad thoughts will be quite frequent. If you keep trying to predict the future, you may feel apprehensive or discouraged. Try to live one day at a time and invest in your relationship with the child. Maybe you want to think and plan your life and your family's future from now on based on your current feelings and experiences. But please remember that society has already progressed a lot and continues to change rapidly, so, the possibilities of life for your daughter or son will improve more and more in the next years.

EMOTIONS

Some new parents are quite upset when they hear the news that their daughter or son has trisomy 21. Sometimes that feeling is postponed for some time (when your baby is very sick, for example, trisomy 21 seems unimportant), but it is rare that it is not experienced.



PHASES

Our experience shows that there are various phases some parents go through:

Denial is a reaction that often occurs. When listening to the news, it is common to think: “this is not happening to me,” “things like this just happen to others.” That cushions the blow and protects them for a while until they are better prepared to deal with the news.

Rage against the world or specific people. “Why me?”, “how could this happen to me?”. You may be able to channel your anger to do something to help your daughter or son. This could lead to a change of priorities in your life.

Depression is an intense feeling of helplessness and sadness. “My world is falling apart”, “I lost my ground.”

In the phase of **acceptance**, gradually you begin to think: “even my baby having trisomy 21, I can live with it. “ Instead of “why me?”, you can start asking yourself “why not me?.” Mothers and fathers should help each other at this stage. Talk about your frustration. This will enable you to better understand what is happening and grow strong together. You will be able to begin to adapt to the new routine. Take advantage of this period to spend a lot of time with the baby and see that she/he is more alike than different from the other children. You will realize that having a daughter or son with trisomy 21 will entail more work, but that you will be able to be the best parents for this child.

Then comes **understanding**. Life begins to settle down and we move on. You will look at your daughter or your son and see the child who needs love and encouragement from their parents. A child full of potential, just like any human being, and who, if given the right opportunities, will certainly surprise you positively in the future. You will see only your daughter/son.

People may experience these feelings in a different order. They can go through all of them at the same time or little by little, and then feel them again later on. There may be times in the future, perhaps when you see a pregnant woman, when a friend has a child or when you realize that your baby does things a little more slowly than others her/his age, that you become sad again. However, your love for the child will only grow, and you will overcome these and any other feelings. “I would not change anything in my son. I like him just the way he is.”

LET YOUR BABY CONQUER YOU

Most parents overcome this early stage as the baby begins to interact, laugh and play, gradually conquering the whole family. From then on, parents begin to forget the “label” that is imposed on the child and start to know their daughter/son’s personality. Your baby will become a beloved member of your family, just another part of your daily lives. From then on, many parents say: “I would not change my daughter for the world.” They begin to enjoy seeing the baby grow and learn. They often find that they, themselves, have qualities that they did not realize they had and their families and friends did not know.





CARING FOR YOURSELVES

“ Our children need us whole,
but for this we need, father and
mother, to be well. ”

Your own health is vitally important. Any birth comes with a complex mix of physical and emotional reactions. In addition, new feelings will surface with your new baby. Expect good days and bad days, as with any child, and allow yourself to cry if you feel like it. You need to rest, like all new parents who have had a baby. Do things that you like. Talk to people who have children with trisomy 21 or other disabilities. Research. Get information. Fear of the unknown can make things more difficult and raise doubts. However, try to search only for things that will help you and your child in that moment. Do not exaggerate.

Allow yourself time to recover. Your feelings are changing and things are getting easier. Get to know your baby. Cuddle her/him, breastfeed or give the bottle and take pictures. Take time for yourself. Go to a quiet place where you can just forget about trisomy 21 for a while. Talk to other parents. The association in your city or health professionals can give you information about support groups for new parents. Pick up the phone. The first time can be very difficult, but it really helps to talk to someone who has had the same experience. Ignore useless comments. Even from people next to you. Avoid too much contact with negative people, who will only express sorrow or even reject your baby. You may feel you do not want to think about trisomy 21 now. If so, just put this booklet aside until the time is right for you.

Oxygen mask and our priorities

On a plane, the stewardess says: “in case of depressurising of the cabin, oxygen masks will drop down in front of you. Place yours first and then help the others sitting next to you.” The message is clear: in an emergency, you must be well first, so you can help others.

We often take the care about ourselves for granted. We can always wait a little bit longer before seeing the doctor, the dentist, eating healthy, exercising... sometimes the situation is even more critical, and we procrastinate even more basic cares such as brushing our teeth and taking medication. It seems like there is always someone more important than us: sons, spouses, work, causes.... we don't usually recognize these symptoms because they can be subtle and not bother many people. After all, everyone is being taken care of, except you, isn't it?

What is worse is that we usually only realize this unbalance when the engine starts shutting down. Then diagnostics pour in - emotional stress, depression, panic syndrome and even stroke, aneurysm, heart attack, cancer...

So take care of yourself. If you don't look after yourself properly, you may not be prepared when the oxygen mask drops down in front of you.

We are all different and react in widely varying ways.

Some of us received the news peacefully, probably because we already had had contact with someone with Down syndrome or had information about it.

Some of us were surprised at first and soon got used to the idea.

Some of us got frustrated and did not believe in what we were experiencing.

Some of us suffered a lot and plunged into the deep end, afraid of the unknown and the future.

Some of us felt lost, helpless and did not know where to start.

Some of us asked for help and others were silent.

What we all have in common is a daughter or a son with trisomy 21.

What we all probably agree is that everything would have been better if the health professional who broke the news to us had spoken in another way. Or even better, if they would have had a more positive view on trisomy 21.

It would be better if the schools would have had a more positive view on trisomy 21.

It would be better if the rest of the family, friends, neighbors and strangers would have had a more positive view on trisomy 21.

It would be better if each of us would have had a more positive view on trisomy 21.

It is based on how each of us looks at our daughter/son that society will change its look. You and I have the opportunity to live and learn and realize that prejudice is something old, meaningless, that does not lead us to a better world.

We now have in our hands the opportunity to throw away all that negativity we heard about trisomy 21 and look at this baby just like OUR DAUGHTER, OUR SON.

DAUGHTER. SON. No label. No value judgment. No more or less. No measurements.

Our daughter/son who came or will come to the world through us.

Our daughter/son to whom we will do all that is within our reach, to whom we will teach everything we know, whom we will love even beyond infinity and whom we will most deeply wish to be happier and more complete than ourselves.

Our daughter/son. With her/his smile, her/his tears, her/his dreams, her/his fears. Her/his limitations, her/his flaws, her/his qualities and her/his difficulties. Our daughter/son with her/his own characteristics.

Does our daughter/son have different characteristics than the majority of those who have 46 chromosomes?

Yes, our daughter/son has 47 chromosomes!

If we can look at our daughter/son as just our daughter/son, forgetting majority and minority, forgetting what others say, the number of chromosomes, the odds ... if we can feel our daughter/son as our child, our journey will be a learning experience.

QUESTIONS AND ANSWERS

WHAT IS TRISOMY 21 OR DOWN SYNDROME?

Down Syndrome is a natural and universal genetic occurrence that has always existed in mankind. In the cell division during pregnancy, there are three chromosomes number 21, one more than the two that are usually formed. Therefore, Down syndrome is also known as Trisomy 21. Syndrome means a set of symptoms or characteristics. Down is the surname of the British doctor, John Langdon Down, who discovered the syndrome in 1866. The genetic cause of trisomy 21 was detected by French geneticist Jerome Lejeune in 1959.

Trisomy 21 is not a disease, so people with Down syndrome are not sick. It is not correct to say that a person suffers, is a victim of or is afflicted by Down syndrome. The correct is to say that the person has or was born with Down syndrome or trisomy 21.

Although Down syndrome is the most commonly used term, in this booklet we deliberately chose to use trisomy 21, since it is the correct medical term, and also because of the negative connotation of the word “down” (in a lower position).

HOW DOES TRISOMY 21 HAPPEN?

Each person is born with 46 chromosomes in every cell. The cells of your baby contain an extra chromosome 21. This occurs in three main forms: simple or free trisomy, translocation and mosaicism.

The most common is the simple or free trisomy (95%), in which an extra chromosome joins the pair of chromosomes 21. In translocation (3.5%) a great deal of extra chromosome 21 is attached to chromosome 14 or 22. It is the only case where there may be a genetic relationship in the occurrence (this tendency may have been inherited from a parent). Mosaicism occurs when not all of the baby’s cells have three chromosomes 21. This happens in only 1.5% of cases.

No matter what type of trisomy 21 your child has, the effects of the extra genetic material vary greatly from one individual to another. Your daughter or son will inherit her/his family’s features and will have his own potential, tastes, talents, personality and temperament. Think of your baby as your daughter/son. Down syndrome is just a part of who she/he is.

WHY DOES IT HAPPEN?

Trisomy 21 is never anyone's fault, it just happens. To date, no one has discovered why it happens. It is not linked to taking medicine, eating foods, radiation, pollution exposure or anything parents have done. Trisomy 21 exists in all ethnic groups and social classes, worldwide. Do not feel guilty.

Some mothers find that they are responsible for having carried the baby in their wombs. Although the chance of trisomy 21 increases with maternal age, 80% of children with Down syndrome are born to women under 35. This is because younger women of childbearing age have more children than older mothers.



WILL IT HAPPEN AGAIN IN A FUTURE PREGNANCY?

Probably not, but you can not say for sure. A geneticist can do a genetic study of the couple and show you the probabilities, but for most families, the chances of having another baby with Down syndrome are one in two hundred.

WHAT INDICATES THAT OUR BABY HAS TRISOMY 21?

There are some signs that are common in children with trisomy 21. First doctors perform a physical (or clinical) test looking for certain characteristics that most babies with trisomy 21 have. Our babies have hypotonia (they are floppy), with very flexible joints. This will improve as they grow and are stimulated. Some of them have flat-looking faces and smaller ears, located a little lower on the head. Usually they have slanted eyes. Many babies with trisomy 21 have a single line in their palms. Doctors often look for this crease to determine if the baby might have trisomy 21. However, some babies who do not have trisomy 21 also have only one line on the hands, while other babies with trisomy 21 do not. The big toe and the second toe may be more spaced apart than usual, among other signals.

“Many misconceptions about trisomy 21 come from outdated information and stereotypes. Learning more about trisomy 21 can help alleviate some of the uncertainties. Try to find out and take a time for family and friends to learn more as well.”



CHARACTERISTICS

Some features that can be observed in infants with Down syndrome

- slanted eyes
- single line on the palms
- flat face
- decreased muscle tone (hypotonia - the baby is floppier)
- flexible joints
- excess of skin on the neck
- tongue out
- slightly smaller ears set low
- small mouth
- small hands and feet
- shorter fingers
- minimum fingers curved
- toes and second toes apart

All babies are different from each other and the same goes for babies with trisomy 21. This means that in some children the characteristic signs of the syndrome are easily recognized shortly after birth, while in others these signs are not so obvious. In any case, your baby will have, as a rule, some physical characteristics of trisomy 21 and will also look like the rest of his family. Gradually, you will notice.

HOW DOCTORS CAN BE SURE?

A blood test will confirm whether or not the baby has trisomy 21. It is a chromosome analysis test, called karyotyping, where they assess the number and structure of chromosomes.

CAN DOCTORS BE WRONG?

It is extremely rare. Generally doctors can diagnose trisomy 21 in a physical exam. There is no need to wait for the genetic test results to tell people about the baby. The karyotype usually takes some time to get ready. Until the results arrive, you may want to spend time getting to know your baby rather than worrying about trisomy 21.

CAN TRISOMY 21 BE CURED?

Trisomy 21 is not a disease, so there is no healing to talk about. It is a permanent condition that cannot be modified. Like any other child, our babies have different types of abilities and difficulties. Their skills are not linked to their appearance. The difficulties can be reduced if you and the people around your child have a positive attitude towards trisomy 21.



HOW CAN I KNOW THE DEGREE OF TRISOMY 21?

There are no such thing as “degrees” of trisomy 21. All people with trisomy 21 are different. There is no test that can be made at birth to show how your baby will develop. This will depend on a series of factors. With the right help, your child will grow, learn and flourish, although this may take longer than usual.



WHAT CAN WE DO TO HELP OUR BABY DEVELOP?

To help your child develop her or his full potential, start as soon as possible with early stimulation treatments (physiotherapy, occupational therapy and speech therapy). One of the things you can do as soon as the baby comes home is to leave her/him belly down to strengthen the muscles of the neck, back and chest. This exercise should accompany the baby for the first few months, so it's good to get used from the beginning. Make she/he get used to it little by little. Start with a minute and gradually increase the time you leave the baby facing down while she/he is awake.

Studies have shown that neuroplasticity can change children development dramatically. New roads can be created in the brain, especially from 0 to 6 years. The more you treat your son or daughter as an equal, the greater the chance he or she will have of understanding the world and overcoming learning challenges.

But the most important is: talk to your baby as you would talk to any other baby or anyone else in the world. SHE/HE UNDERSTANDS!!

Do not believe 100% in health professionals, in books, in texts or in the other parents. Let your son or daughter show you who he or she is: a blank page, ready to start to write her or his story.

BREASTFEEDING

Breastfeeding is very important for babies, but for those with trisomy 21 it can mean much more. Sucking from the mother's breast strengthens the baby's muscles in the mouth, digestive and respiratory systems and even the hearing system, preventing reflux, ear infections and preparing the baby for speech. It is also a special and unique moment between mother and baby and contributes to strengthen the immunity system of children and their healthy growth.

WHAT WILL OUR BABY LIKE?

Like all babies, yours will eat, sleep, cry and have to change diapers. Like all babies, yours will want attention, comfort, warmth and affection. Within a year your baby will probably be able to sit, roll over, laugh and lavish charm to your family and friends.

IS OUR BABY HEALTHY?

Babies with trisomy 21 can be healthy and have as many medical problems as any other child. About half children with Down syndrome are born with a heart condition, sometimes intestinal problems. Occasionally babies need to undergo a surgery soon after birth or when they are bigger and stronger. Do not leave the hospital before doctors examine the heart and digestive system of your child.

Some of our babies, because of hypotonia (floppy muscle tissue), can cool more easily than other children. Because they have narrower ears and airways, they may become blocked more often. Hearing problems, vision and thyroid are also more frequent than in the general population. You can find information on routine medical tests and health care on [Movimento Down](#) website.



The list of possible medical problems, at first, may seem daunting. But it is important to know what tests need to be done so that, in case something happens, your baby can be examined and treated as soon as possible. On the other hand, what few people know is that having trisomy 21 decreases the chances of the person developing certain diseases, including various cancers.

I HEARD THAT PEOPLE WITH DOWN SYNDROME DIE EARLY. WILL THIS HAPPEN TO MY CHILD?

Like anyone else, it is impossible to predict how the life and health of your child will be. The good news is that in recent years progress in medicine has significantly improved the quality and life expectancy of people with trisomy 21. The numbers are impressive and encouraging. In 1929, people with Down syndrome lived an average 9 years. This jumped to 60 years old these days, with many people living to 70 or more. That is a similar expectation to the general population.

WHEN IT IS TIME, SHOULD MY CHILD ATTEND A REGULAR OR SPECIAL SCHOOL?

Several studies show that diversity in the classroom improves learning, life and citizenship of all students. Children with trisomy 21 benefit from learning experiences with their peers in inclusive schools, along with students without disabilities. And children without disabilities also benefit from it. Students with trisomy 21 have the right to inclusive education alongside their non-disabled peers guaranteed by the United Nations Convention on the Rights of Persons with Disabilities. The school cannot refuse to register your child, or charge extra fees because of trisomy 21. It would be discrimination. This also applies to nursery schools, courses, sports and religious classes, etc. The school must provide all necessary tools so that your child can learn and grow along with the other children of the same age.

WHAT WILL OUR CHILD BE LIKE AS AN ADULT?

Your baby will grow to become a beloved adult in the family, according to the interests and values that are passed on to her or him. Our parents tell us it is better to handle the baby you have now instead of worrying about the teenager or adult you think he or she will turn into. The prospects for our children have improved a lot compared to the last generation. Do not base your ideas on outdated information or the lives of older people who did not have health conditions, encouragement and opportunities for social inclusion that we see today.

In Brazil, more than 50 young people with Down syndrome attend university. An increasing number of them work, date, have a home, contribute as participating members of their communities, like anyone. Remember that much of your child's condition in the future will depend on what you do for her or him at this moment. It is essential for their development that their parents believe in their potentials.

WHAT IF I CAN'T ACCEPT THE BABY?

Some families in a first impulse say they do not want the baby. Almost always this feeling changes as these parents get to know their own child rather than “the baby with trisomy 21, with an unknown and scary future.” Occasionally, feelings of rejection persist and parents decide that the baby should be given to adoption. The child should then be referred to the Childhood and Youth Court in your city. There are many families who would be happy to adopt a baby with trisomy 21. In some countries there is a waiting list for adoption of children with this disability.



SPEAKING ABOUT YOUR FEELINGS TO THE OTHER SISTERS AND BROTHERS



As mother and father, you are the best suited person to decide how much information is appropriate to give to your other children, depending on their age, level of understanding and curiosity. Do not be afraid to tell the children as soon as possible. Talk honestly and openly. They may not understand or remember all the information, so follow their lead. Answer the questions as they arise. You may want to clarify things as:

- Brothers and sisters are very important for a baby.
- Your sister/brother will want to participate and do the same things you like to do
- It may take longer to be able to do some activities
- It will be great if the baby could count on your help to learn!
- It's not your fault the baby has trisomy 21, it's just happened.
- You do not have trisomy 21.
- The baby can not pass trisomy 21 to you.
- The baby will always have trisomy 21.
- We love you very much and we love the baby as well.

Your children will follow your example. If you treat trisomy 21 as just one aspect of your baby's life, so will your children.

OTHERS

Breaking the news to family and friends can be very difficult. Only you know when and how best to tell other people. Sometimes it is better to talk just to close friends or family, so you have someone you can talk about it to. Other times it is easier to tell the most talkative of your friends and ask them to spread the word so that people know without you having to tell them. Sometimes it is best to wait until you are better prepared yourselves to break the news to others, in order to be able to deal with their reaction. Only you can decide how much of the story of your baby you want to share with people and what words to use.



“As soon as I got out from the hospital I sent an email to all my friends and family saying my daughter was born with trisomy 21. I said that she was beautiful and we were in love with her. It was the best way I found to break the news to others and leave no doubt that we were receiving that baby with open arms, and we expected everyone to do the same”.

Sometimes family, friends and people you meet on the street will say very insensitive and hurtful things. Try to ignore those comments. They are often based on a lack of information. People will follow your example. If you are open, they will be honest and positive with respect to trisomy 21. Distribute copies of this booklet among your family and friends. When you go out with your baby, you may not be sure that other people realize that she/he has trisomy 21. You can choose whether or no to mention it.

When my daughter was born, almost five years ago, I lived one of the best moments of my life. After two involuntary miscarriages, the little daughter we had both planned and hoped for materialized there - lovely and fluffy as imagined.

The pink baby was discharged with a high score from the doctors - Apgar 9:10! - and went straight to the room without getting in the incubator. They set her in the crib beside my bed, and I would never grow tired of looking at my daughter. I was delighted! That small child we both dreamt about came to complete our family. I didn't need anything else to be completely happy!

My happiness did not last long. The pediatrician on duty entered the room. My daughter slept and I still had a smile on my face. I wanted to ask the doctor a silly question about her appearance.

- Doctor, aren't her eyes a little "Down"?

I already knew the answer, of course it could not be. As at the time I was 39 and knew that the likelihood of having a baby with Down syndrome was greater, I took all the tests, including genetic ones, and they all proved without a doubt that the daughter I expected did not have Down syndrome. But nobody told me that medicine is not mathematics and medical errors happen. For all that, I was not prepared for the doctor's answer:

- Yes, they are, and she has several other signs ...

- What?????????

And that's when my state of grace turned into disgrace. The question that intrigues me is: where was that idealized, fluffy and healthy daughter, who had become reality for a few hours and ended up becoming our worst nightmare? She was still there, quiet, sleeping in front of me. Blinded by the tears of my own prejudice, I was not able to see her anymore. I, who considered myself well - educated and informed, who did not discriminate anyone, thought my happiness and the happiness of my family would end with a child with disability.

Eventually, I managed to see my daughter as any other girl. And only then did I realize that I had been raised to discriminate against people with intellectual disability.

We are not born with prejudice. It is societal value we are exposed to and acquire. And when we receive a child with a disability in our family, we must face our own prejudice and get rid of it as fast as possible.



YOU ARE NOT ALONE

“ Parents are the greatest collaborators
to the development of their children ”

About one in 700 babies is born with trisomy 21 around the world. There are many associations that advocate for the rights of people with trisomy 21 and other disabilities in many countries, that offer information and support.

HEALTH AND MEDICAL FOLLOW-UP

Now that your baby is born, you need to check her or his health conditions. As we mentioned earlier, people with trisomy 21 often have cardiac and digestive and intestinal issues, that need to be treated as soon as possible. Besides, it is very important that you pay attention to the specific clinic follow-up protocols and growth charts adapted for people with trisomy 21.



“I wish I had gotten in touch with a family, to understand how the development would be, expectations, etc...” ”

Dad, I know you are shocked. I have just been born and they told you I have a name that is different from the one you gave me. I heard the doctor tell you I was Down. I don't know what that means, but I can feel it's not good. I saw you and mom cry and you still look like you are attending a funeral. I have been observing myself, and I haven't found anything weird about me. I don't have antennae or screws. But every one that comes into the room seems to be surprised to see me and sorry for you. I am sure this moment will pass and you will treat me as any other son, but I am concerned with some things I heard, and I thought it best to write to you before it's too late.

They said I won't be able to do lots of things. Where do they find the nerve to say that? I'm not even one day old and they are already sentencing me? Dad, don't believe in anyone. But believe in me. I am sure that if you and mum trust that I am capable of doing anything, you will help me in each conquer. Dad, don't get anxious if I take longer than other kids to do stuff, this only makes things worse. Play a lot with me, let me try to do everything. Give me your hand when I need it, but don't stop me from learning stuff and trying to do things for myself.

I also hear a doctor geneti-something tell you that you should seek for some exceptional organizations, that I should go to a special school. For what I understand, these are places where they send people who are born different. It sounds nice, but does that mean they will not let me play with all kinds of kids? That I will not learn anything but socializing? I want to go to the same school all children go to, after all we are different, and it is in diversity that we learn not to have prejudice.

I liked the couple that came here with the girl that has the same syndrome I have. The one that said that she goes to a school-school. Did you notice she read my name at the maternity bracelet? True, she didn't know what newborn meant, but her parents explained it to her. I know that if you believe in me and send me to a regular school, you and mum will have more work. But in return I will have the chance to become a real adult in the future and not a constant concern for you for all your lives. Isn't it best to work harder now?

They also say you will have to face rude and prejudiced people. But wouldn't you stand up for me anyway, if I didn't have what I have? Besides, you know that sons normally outlive their parents. If you don't think about this now, what will become of me when you are gone? Dad, I believe and trust you and mum. All I need is that you have the same trust in me.

Love from your newest son

A LIFE IN THE PRESENT, A FUTURE AHEAD

As hard as it may be, try not to be concerned about the future. Focus on now and on what there is to be done, and don't miss out enjoying the phase of first infancy, that is so important for you and your baby. Science and the civil society have been moving quickly towards the improvement of life perspectives for your child.

The first six years of life are crucial for the development of the child, and it is very important to count with professionals that may guide you about early intervention or stimulation. Early stimulation, along with being included in the community and most of all the love from the family, are the ideal base for the growth and progress of your child.



Even though your child shares somethings with other children with trisomy 21 (an extra chromosome 21), each one has a unique development pace and it is impossible at an early age to identify which talents and limitations a specific child may develop. The parents are the greatest collaborators for the physical, emotional and psychological development of their child, with the guidance of qualified professionals.

A MATTER OF RIGHTS

International and local laws assure the enforcement of rights for people with any kind of disability. Above all, they have the right to be who they are, not more or less than anyone else, and to coexist with all persons, at home, at school, at work and within all layers of society, with equal opportunities as other people.

If you have any questions about legal aspects concerning your child, please address local disability associations. Don't rest in doubt. Learn the rights that protect you and your child and have them enforced. Don't miss out on reading the Convention on the Rights of People with Disabilities:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

DOWN SYNDROME IN THE WEB

You are not alone. You may find addresses of associations, internet support groups, bibliographic reference and related links in our website:

<http://www.movimentodown.org.br>

At Down Syndrome International website, you will find information about associations on trisomy 21 in dozens of countries:

<https://ds-int.org/down-syndrome-your-country>



I was born a bit different from other kids, but that's no reason for you to be sad! I have trisomy 21! That is because I have 47 chromosomes in my cells, instead of 46 as anyone else... But apart from this extra chromosome, I am a baby like any other one! I love to sleep, to eat, to listen to music, to see colorful things! I love to be held and played with!

When I grow up, I will learn everything the other kids learn, but at my pace! I learn slowly, the way I can! I will walk, speak, run, count, tell colors, read, write... everything at the right time! You don't need to worry!

Of course I will need a bit more attention than the kids who do not have trisomy 21. This is called "early stimulation." The doctor will explain it to you. That's why you will have to take me to places for me to exercise (physiotherapy), work on my mouth, cheeks, tongue (speech therapy) and some other fun activities!

After that, when I am a bit bigger, I will be very naughty! And you need to educate me properly so I do not become a wild child. A wild child is a child who does everything she wants, and this is not nice! Well, I guess you get me.

But you will still have many questions, and you can clarify them all with the doctor and with people who work with children like me. There are also some cool internet groups where parents of children who also have trisomy 21 talk about lots of stuff. It's cool there, they talk about stuff that happen to us! Well, I'm tired from this talk... I guess I'll eat and take a nap now. I love you!

Your baby.





www.movimentodown.org.br

www.facebook.com/movimentodown

SUPPORT



FORDFOUNDATION

Na Linha de Frente das Mudanças Sociais

Movimento Down is an initiative of MAIS - Rio de Janeiro, and is affiliated to FBASD, DSI and RNPI



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