

# I'M NOT WEIRD, I'M A SPECIAL EDITION! WITH AN EXTRA X.

What it means to be a "SuperWoman"

The TriXy book for teenagers and families

about life with Triple X.

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<https://www.triple-x.info>



One Sunday morning around 5:45h, the sun was just rising, and little TriXy was born. Her mother and father were overjoyed. They were happy about the arrival of their daughter in the world. They loved their little girl from the first second. She was their little miracle that had become reality. And even more than they knew at that moment...



TriXy was getting bigger. She was a sweet baby and easy to take care of, content, calm, smiled a lot, a little golden treasure. She learned to crawl and walk, not quite as early as other toddlers, but she achieved everything, just like the others. And anyway: every baby has its own pace to learn.

When she was able to explore the world on two legs, she was curious and looked and watched a lot. She was a real sunshine, much to the delight of her parents.

Life with her was perfect.

In kindergarten, everything went well. Sometimes TriXy was a little sad and sometimes she got frustrated or angry a little faster than other children. But no one really noticed.

Time passed and TriXy made her way, just like other children. She did everything at her own pace. And in kindergarten, she didn't have to reach any "goals" yet. She had as much time and space as she needed.



At 7, TriXy started school. She was so proud, and so were her parents. She liked school and learned many things. TriXy laughed and played, but also realized that learning often wasn't as easy for her as it was for others. And that sometimes it became too much for her to sit in a class with so many children for so many hours and have to concentrate. There were just too many noises and movements around her, which she perceived as very loud and colorful. Then she started drawing. Often she drew how she felt. These were colors and patterns. Her inner world became visible, only no one saw that in her pictures. Sometimes she would just stare into space at the wall. There she saw figures, shapes or patterns. That calmed her, so she could listen better. Preferably to a single person. But it was not so noticeable, because she was quiet and sweet and very polite to the teachers and classmates.

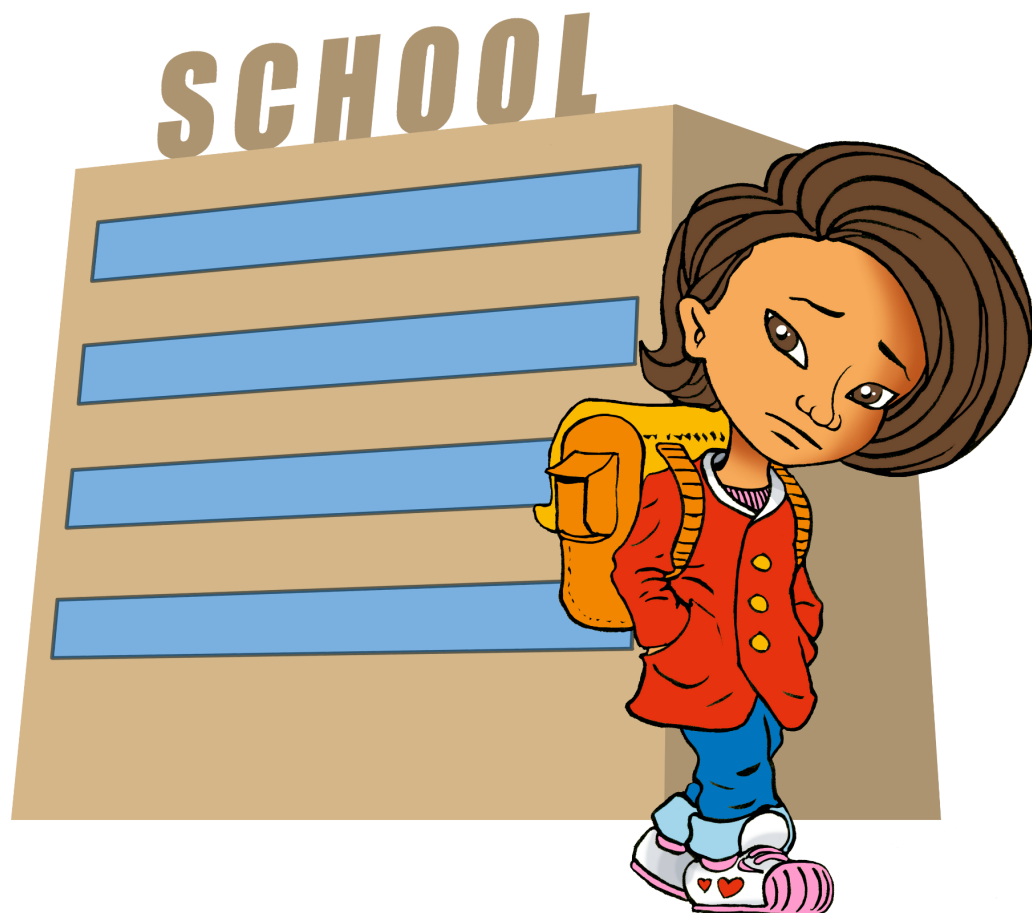


Only sometimes, when it became too much and she didn't get a break, she suddenly became sassy. But her classmates didn't understand that. For them, everything was fine with the hustle and bustle around them. Their "filter" worked, TriXy's did not.

The first year passed, and so did the second. In the third year, TriXy was now almost 10 years old, and some classmates started to tease TriXy.

Only a little at first, then it became a little more. It was easy for classmates to tease her because she didn't have much self-esteem, didn't believe in herself, and when they teased TriXy, it didn't take long for her to cry or get snippy.

She wanted to go on playdates after school, but the others wouldn't. They excluded TriXy but didn't really know why. TriXy got sad, wanting to be like the others. Have as many friends as they did. More and more often frustration came up in her because her classmates were so stupid to her or when learning or other things didn't work out that way. Her classmates wanted to play with her less and less and called her weird. And TriXy's mother was also shunned more and more by the other mothers, which also made her sad.



But TriXy was doing her thing. She learned to draw great, she used her wonderful, rich imagination. Because she could do one thing very well, better than the others: She perceived the world especially finely, with all her senses, seeing, hearing, tasting, smelling. She recognized patterns in the things around her, the wallpaper, for example. She heard airplanes long before others saw them. She saw the tiniest little animal in the grass.



Her world was full of wonder. Every day, every minute, every second. She was a wonder among wonders. Her world was never boring and if that (boring) was the world around her, then she was very busy with her wonderful world in her head. The other people didn't understand that or didn't notice the fine little things.

But inside TriXy, everything was quieter than outside, more colorful than outside, friendlier than outside. Here her world was in order, here she felt comfortable, but also a bit lonely.

In her world everything fit, there was peace and quiet. Not like in the classroom, where wild boys and sassy girls "raged" at their own pace and sounds like a whirlpool, a giant wave, a massive noise surrounded her.

It was as if there was a filter missing outside that everyone else seemed to have.

In TriXy's inner world, shielded from the outside, her own filter was working.

The world was beautiful and peaceful. But not everyone around her

understood that. Most of them said, "Speed it up! Why don't you understand?

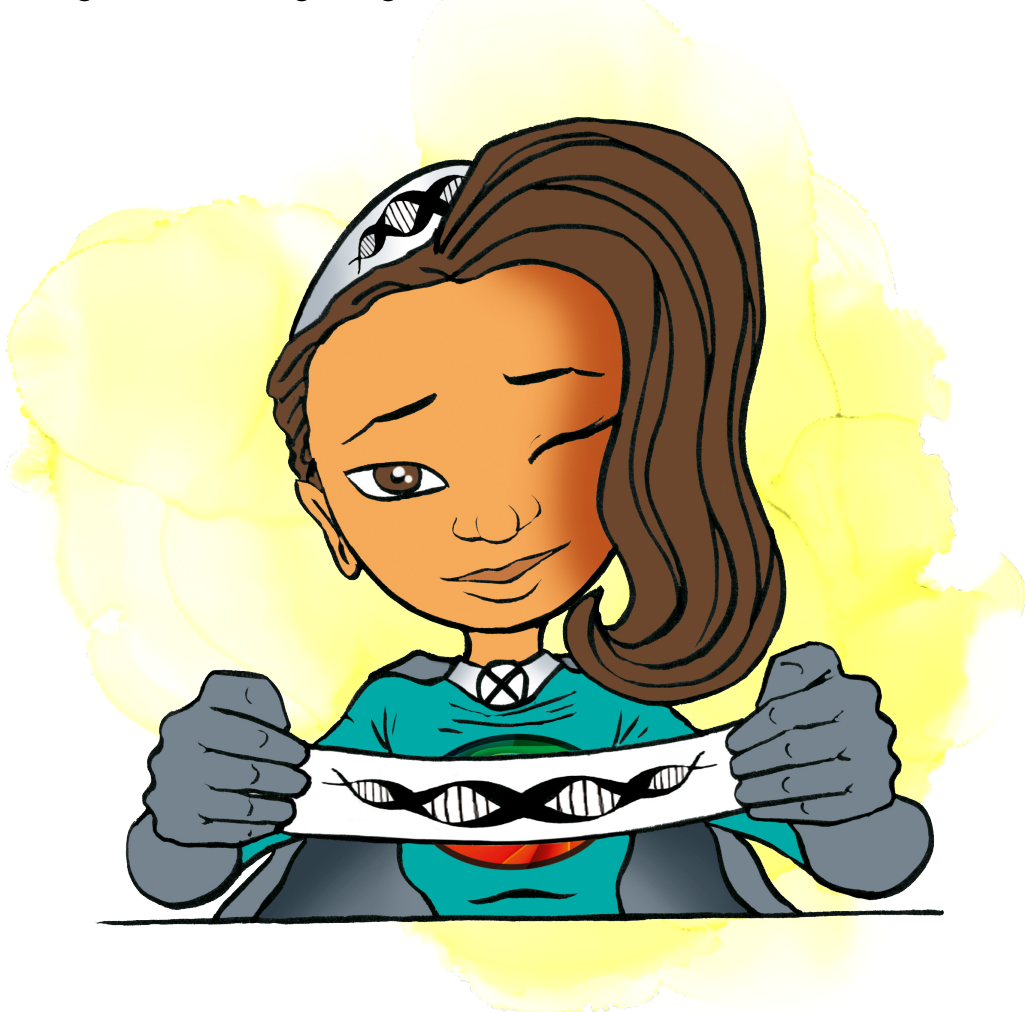
Why are you so funny? Are you stupid? You're so sassy." This hurt TriXy a lot.





Funny? Funny, TriXy didn't really feel that way. She had one or two friends who understood her and saw the world similarly to her. But the others? For TriXy, they were weird, loud and annoying. Her parents noticed that, too. They hadn't worried so much until now. Because so far it was going well. But they started worrying, sad for her.

But now they remembered what the doctors had once told them: "You have a healthy, pretty daughter, she can have a great life, like other girls. But your daughter is a miracle because she has something more than others: An extra X chromosome! Three instead of two. That's something very rare." At the time, the parents had been told there was nothing to worry about, that their daughter would probably grow up tall and slender, perhaps have beautiful almond-shaped eyes and need a little more support in school, but nothing more. Everything would be fine.



It became also beautiful first years with TriXy.

The parents had almost forgotten the extra X. But now they remembered. They wanted only the best for their beautiful daughter. They started to read. They searched the internet for information. They didn't find much at first, because the third X had many different names. It was such a rare thing, it was not obvious, their daughter was pretty and nice and didn't cause many problems either. Life with TriXy was fun and they did many nice things together, like other families.

The thing with the other kids and school was exhausting for everyone. Well, and that TriXy forgot more about what she had actually already experienced or that she was often much more sensitive and quicker to anger than others. And that she more often bumped into something, knocked over or even fell down. The parents noticed this only now on reflection, but of course they loved TriXy just as much as before.

Often they needed more time with TriXy to get things done or sorted, to motivate her, to keep her room or grooming tidier. They needed more patience than average, staying more focused and attentive. But they did and loved their daughter, even if sometimes she was emotionally more distanced, not so cuddly or smiley as others. They loved TriXy and tried their best to support her and have her live a good life.



So they searched for more information on what they found as Triple X. It was also called TXS, Triplo X, 47, xxx, Trisomy X, and Super Female Syndrome.



But most of the publications on the subject were in English and came from America, England or the Netherlands. The parents were so amazed and surprised at how much research there was already on this "invisible topic" and what they did not know before.

They also found other parents and families whose girls had Triple X and they realized: we are not alone! They found people in many countries and groups, there were meetings and conferences, in real life and online. The parents couldn't believe all that was available. And they were happy because suddenly they didn't feel alone anymore.



They were especially surprised because suddenly there were explanations for some of the problems they had had but hadn't necessarily understood. They learned that Triple X exists all over the world, every 1000th girl born has it, but only 10% of them ever knew it. That means out of 100, 90 didn't even know! And out of the 10, 5 had only minor problems and the other 5 had a little more. And the things that were different in the lives of the TXS girls, they were the same all over the world. But very rarely were there doctors or help that families could just get like they could with other health problems.

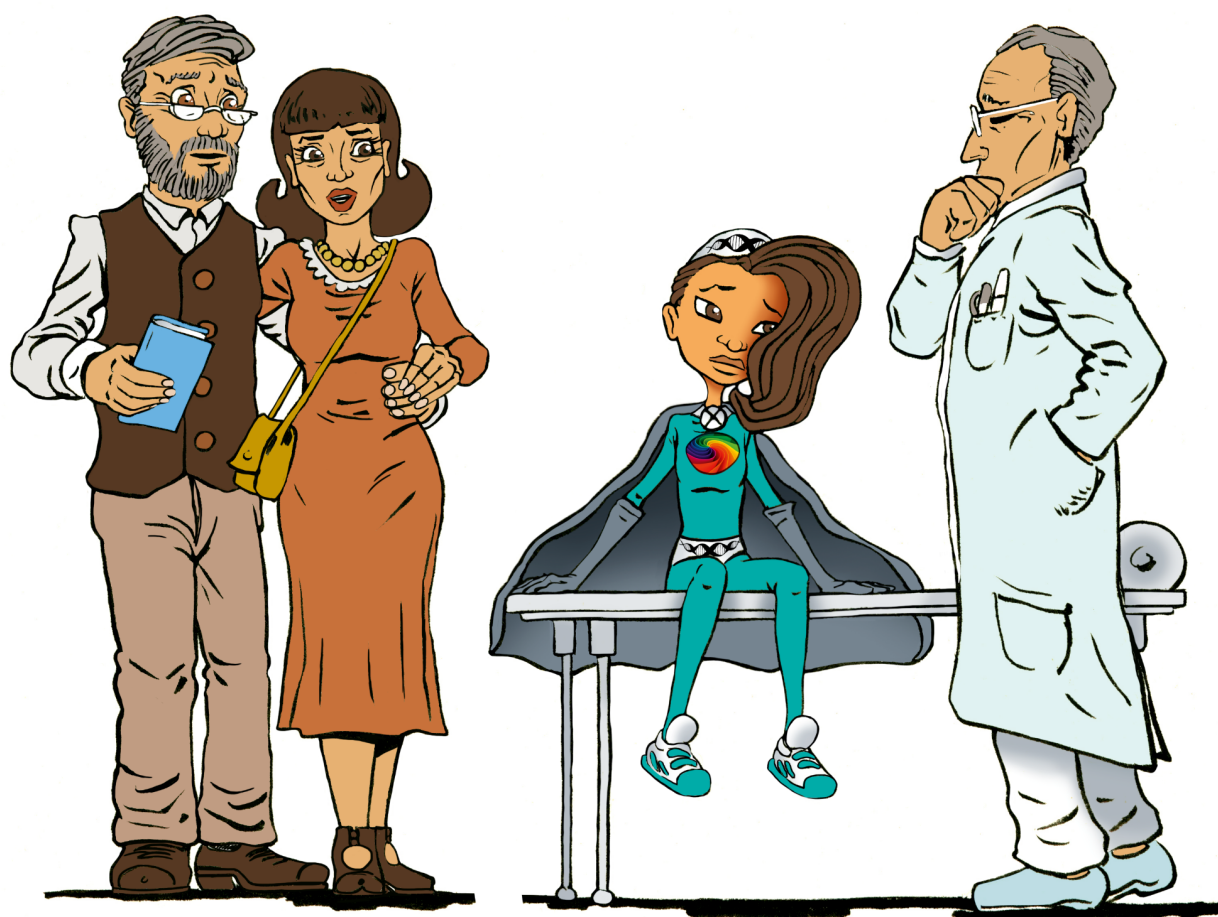
Most Triple X families just did their best to help their daughters, love them and deal with what was going on every day. Just like everyone has to do in everyday life. Only now the parents learned that some things happened more often to the TXS girls.



For example, to bump into something, to stumble, to forget something, to be sad or angry more quickly, to have few friends, to sometimes simply not understand the world. That the hands or the body could sometimes tremble for no apparent reason and if you touched them, they sometimes screamed as if you had hurt them badly, while nothing had happened at all. The perception of the world around them had different rules than most people. That there were problems with the heart, muscles, coughing, breathing, kidneys or stomach ache. Not being able to control the anger that came very suddenly and then yelling and raving and arguing with others more than usual. That language was difficult because words or sentences didn't make sense, letters blurred when reading, shopping, gym club and hanging out like other girls wasn't fun. Playing games or drawing or meeting with individuals was nicer and more comforting for the TriXies than being in a group. But this made them quite lonely. And that gave the parents a lot to think about.

So the parents got smart, got to know and understand Triple X better. They realized when they talked to other TXS families that many didn't know how to tell and explain Triple X to their daughters and also to teachers, doctors, siblings and relatives. And most importantly, WHEN best to

tell the girls. Many families waited a long time to do this. They waited for the "perfect time," but it was somehow never there. And it was also doubly hard to explain to other people what you couldn't see from the outside. Some parents were also ashamed. But that was unnecessary because TXS is not bad and no one can help it and no one did anything "wrong." TXS is a coincidence, a folly of nature.



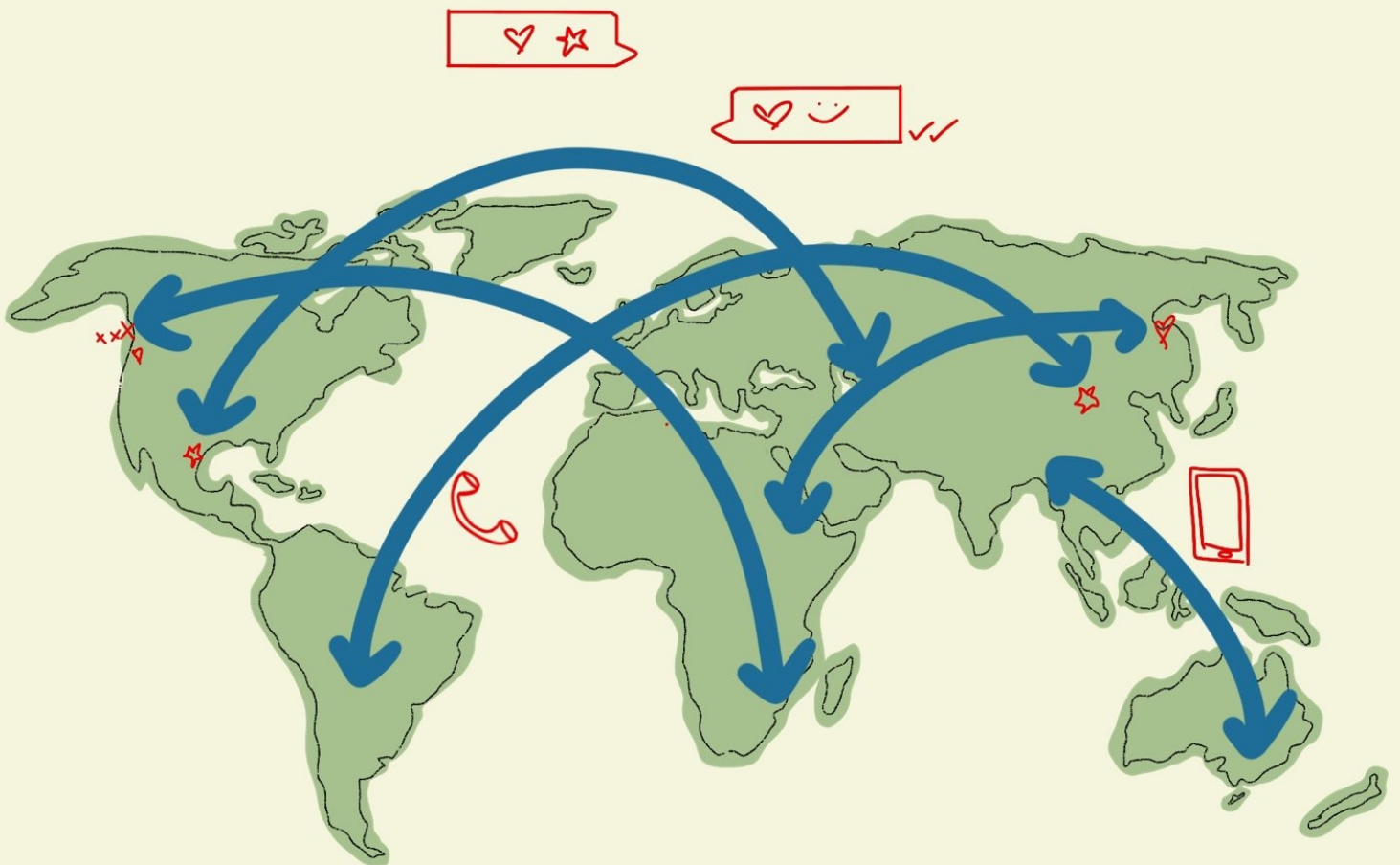
How do you explain something that you can't see from the outside, but which causes problems in the family, school, everyday life, etc. and often leads to arguments?

The parents talked to each other and consulted.

Because they wanted their daughters to do well and also to be able to grow up themselves with understanding what their TXS is, what it does to them, and how to bridge problems that arise in the process for the girls. They wanted to find ways to give the girls peace, love, acceptance, and trust. They wanted to make sure there were ways to improve some things like having a bad memory, so not being able to remember everything, not being able to handle frustration and anger well.



Some parents built a website and groups and chats and even an app for the Triple X girls and their families. They made contact with each other, the TXS girls could suddenly talk to each other and meet on the internet or for real. Even though they all lived across their countries and around the world. They were no longer alone. They could learn from each other and support each other.





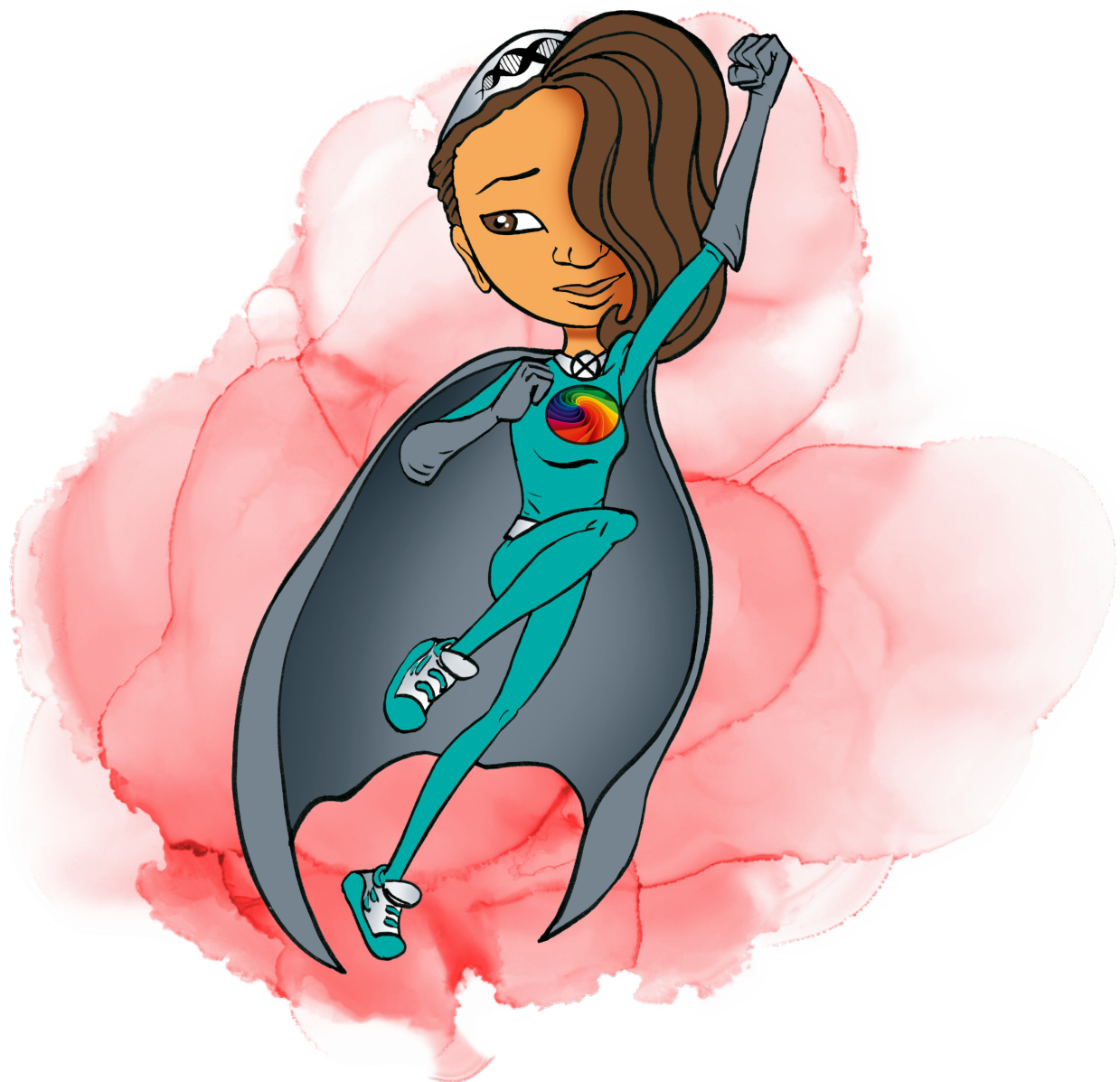
TriXy was now already 14. In school, there had been some severe problems with other classmates, and in the sports club she was not happy. But in the Girl Scouts, she felt great. She was part of the group, and was not excluded, but accepted as she was. She dared to do more and more. She became a member of the youth fire department because even there the others were fair to her, she was treated equally, and that felt good.



The parents didn't give up, found a school where the teachers gave her a real chance and listened to the parents when they asked that the teachers have a little more patience with her, and also support her socially and emotionally. So even talking to classmates sometimes TriXy needed a little more support from them too. TriXy did so well that Ds became Cs, Bs and As. Finally, things were going smoothly again. Because others accepted her and no longer excluded her.

The biggest problem in school was cracked. Also because her parents fought for TriXy and she got some support like other kids with challenges like ADHD or autism usually got. Just a little understanding and support were needed, and then things worked out at school.

TriXy really had fun again, even made some friends, and also dared to stand up for her challenges herself and be very open and relaxed about the fact that she was a young "Super-Woman" with an extra X chromosome. She said, "Hey, who or what is 'normal'? Everyone has his or her own peculiarities. Mom, for example, has thick glasses and is almost blind as a mole. And my speciality is simply an X."

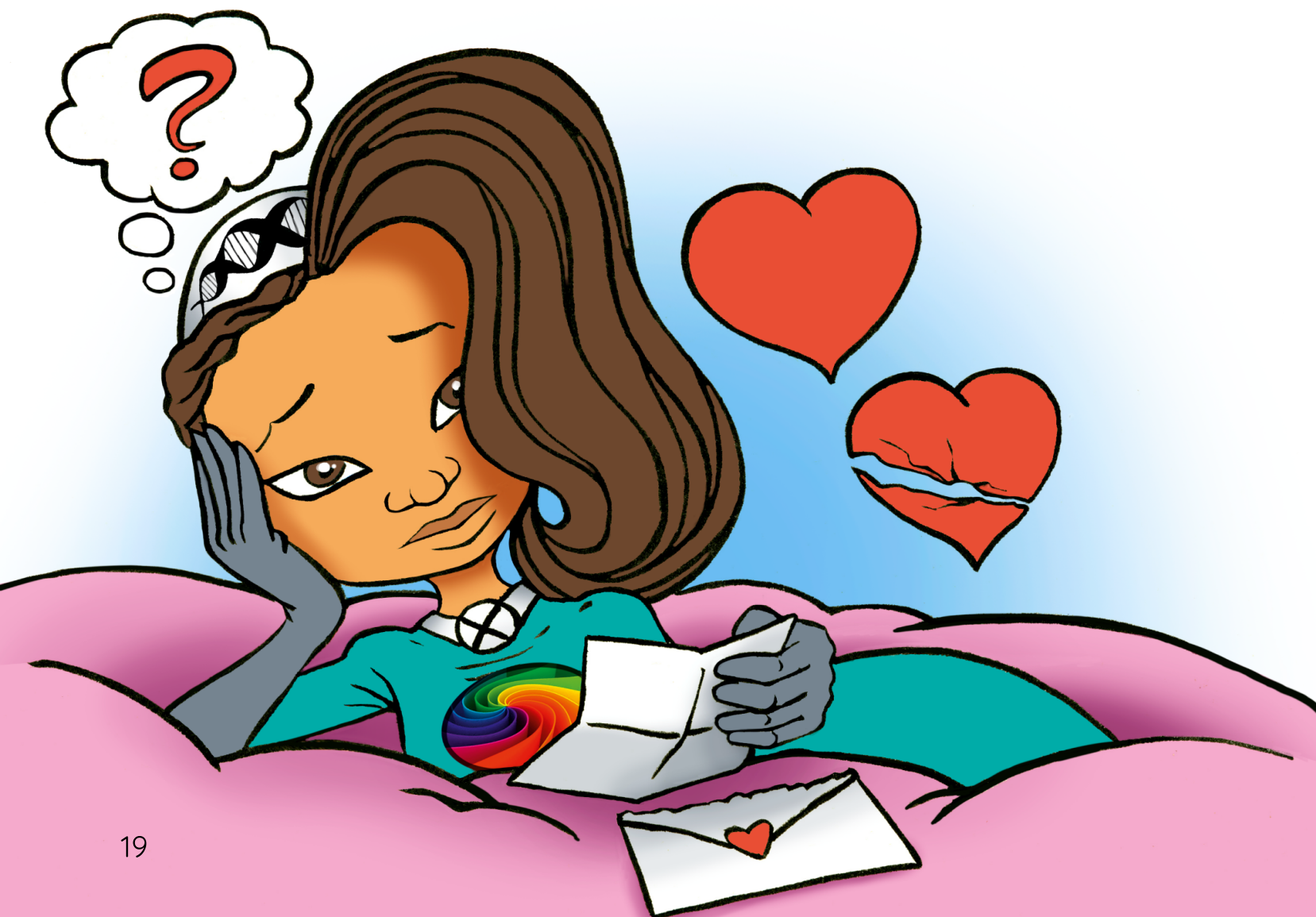


She learned to deal with it better, answer questions about it, and just live with the fact that sometimes she had to try a little harder than others. But fun in life she had now, like everyone else. Nothing held her back anymore. She did everything at her pace and even sometimes asked for assistance when she needed it. Or just took her TriXXXy app on her phone to help. She learned to understand herself better. But then again, everyone does that, right?



TriXy got older and older. Some problems disappeared, others came and sometimes disappeared again. Soon she had a boyfriend. Being really in love and all. She graduated from school, chose a profession that suited her and fulfilled her needs for peace and rules and requirements.

Because with the knowledge of what Triple X entails and also how to help herself, it was not a bigger problem than with other young women. Her parents and her own open approach to extra X made that possible. And every day that all the TXS families who knew were dealing with it confidently, the situation got a little better for everyone. The "invisible" syndrome became more visible, more known and lost its "terror". And there were quite a few families in the world because there were several million women with TXS. Quite a lot for such an "invisible" thing.



TriXy's life is still young. So many beautiful things will happen, but also things that are not always easy. But she and her parents, siblings and friends will overcome the challenges.

And YOU, dear TriXy, who is reading this, can do it too!

We believe in you, Super-Woman. You can do it!



## Facts

Please note: TXS has a very broad spectrum. Some TriXys experience big challenges, others almost none. This book shall offer an overview of what possibly *can* show up. Not MUST! If you see just a few things you have, super. If you have these mentioned traits but did not notice yet, you get the idea, that the reason could be Triple X.

Want to know more details about Triple X now?

Here are the most important facts:

First of all: Triple X is nothing bad. It is rare and still very little known in the world, but there are much worse problems you can have, especially with genetic variants, when the genes are arranged differently than usual. For Triple X syndrome<sup>1</sup>, there are many approaches to dealing with it and managing problems that arise because of it.

So don't be afraid. Everything will be fine! Especially if you inform yourself well and that's what you are doing. With a little bit of good information about it and support, it is feasible that you can do pretty much everything that other girls and women can do. And live a happy, interesting life doing it. For example, if you need to tidy up, take a look at strategies or tips from people who are good at tidying up and have experience with it, and try their suggestions yourself.

Here are a few tips:

1. Accept the diagnosis and most importantly, don't see it as punishment or bad luck, everyone has their challenges to live through and this is just yours.
2. Inform yourself and others! There is already a lot of information from the last decades that helps to understand what TXS is and to deal with

<sup>1</sup>syndrome = certain collection of symptoms  
symptom = indicators

it in a relaxed way. You can easily find it in this book, the website [www.triple-x.info](http://www.triple-x.info) and the app "TriXy" (available in the app stores for IOS and Android).

3. Help yourself! Still young and don't know how to help yourself with TXS you barely know? No problem, there is help, take it! And get to know and observe yourself better. For example, write in a journal when something happens that is different from others.
4. Trust your parents and supporters! As a young person, it is often difficult to trust others that their experiences can be useful to you. People don't like to be told, we understand that. But since TXS is not an everyday topic, you will need the support of people who know about it (and there are already quite a few of them worldwide). Learn from them. They are happy to help you.
5. Trust life! Often you don't know why something has to be difficult at the beginning instead of everything going smoothly. You grow with your challenges and you are not alone with TXS! Take advantage of that and many things will become easier.
6. It is also not easy for your parents and siblings, friends and environment to deal with your "invisible" syndrome. But: They want to support you and make your life better. They just have to learn to understand what TXS is and how to deal with it. Be patient with them, explain to them when something bothers you and also how the world feels to you.
7. If you read all the information now and not everything applies to you, then be happy! Don't look for the problems that don't apply to you. And don't use the challenges you see in yourself as an EXCUSE!!!! They are not! You can do almost everything. Don't be afraid, it will never all occur with you or any other TriXy. Each of you is unique, a very unique personality with a wonderfully unique profile, like a diamond.

## Basic information

And now the important basic information about Triple X Syndrome:

- It has different names: Triple-X, Triplo-X, Trisomy X, 47, xxx, Triple-X Syndrome, SuperFemale Syndrome, 3-X Syndrome.
- It was discovered in 1959 in Edinburgh, Scotland by Dr Patricia Jacobs and her team.
- About one in 1000 women are born with TXS worldwide.
- Only about 10 % of TXS women are ever diagnosed and told they have it.
- Most are discovered by genetic testing before birth or late when they are adults.
- In lists of rare syndromes, it has the code: IDC-10 index: Q97.0
- It is a genetic variation (trisomy), the X chromosome is present 3 times - normally a woman has two X, in TXS three. This occurs during early cell division, meiosis and is not "curable" (but it doesn't have to be, you can live with very well).
- TXS therefore only occurs in girls.
- TXS can be well supported by therapies and support. A normal life with very few or no restrictions is quite possible.
- IMPORTANT: about 50% of TXS girls show no or hardly any problems at all, nothing or much can apply to a TXS carrier, but does not have to.



- You may have more problems with everyday life or be overwhelmed by situations with many people and volume faster and more than others. This is not uncommon, but you can improve a lot on this with some training.
- The problems can be different for each TriXy, it's called "the spectrum is wide", e.g., parts from autism, ADHD, anxiety, etc. CAN occur, but don't have to. Some TriXies are more anxious than others, some are quite brave. Everyone has their own way. There is no need to be ashamed of it. And certainly not about misdiagnosis by doctors who don't know TXS well enough and so often guess at the wrong thing.
- Your self-esteem may be a little less than other people. Self-doubt may be more prevalent, but it doesn't have to be, you're not doing anything wrong.
- Mostly TriXies don't have many friends and being integrated into social peer groups, like sports teams or so, is not so easy as for normative kids or adults. Try to find social groups like scouts, fire brigade or other socially focused projects. Usually, those groups are more open-hearted and supportive.
- Memory can be a bit more difficult, remembering things is not so easy, and sometimes already experienced or known things are gone again. This is not your fault and you are not stupid. Your brain does it that way. But there are tricks to deal with it and to help yourself to remember things. Look up memory training / mind palace.
- A TriXy often perceives stress differently than other people. TriXies can usually feel and perceive things and change very finely.
- They have a very sensitive "antenna", especially with time, sounds, feelings, movements and in large groups of people.

- Your working speed will probably be a bit slower than others. The conversion of thoughts into actions often does not work as fast or occasionally not at all with TriXies. This is called dyspraxia. A difficulty in application. On the other hand, you may do things slowly, but also very precisely and can recognize mistakes very well.
- This can often lead to distractions from the subject or his thing, the concentration is then sometimes gone.
- If someone complains (parents, teachers, classmates), then it is often not easy for a TriXy to stay calm, the frustration quickly becomes very strong. And it often remains longer than with other people.
- If someone around you has patience and understanding, things usually get better soon. If someone complains and puts pressure on you, then a TriXy usually explodes more quickly or becomes sad or sassy. And cooperation doesn't work anymore for a while.
- Then there are challenges with the so-called "impulse control". This means that your amygdala, a brain gland in the forebrain that controls anger and heartbeat and excitement, then messes up and staying calm doesn't work well, you can also freak out sometimes. Usually calmness and mindfulness exercises help (for example in our app).
- Your body is functioning well, but peculiarities such as abdominal pain, constipation, tremors, focus problems, problems with kidneys, heart, lungs, hormones, having children and early menopause (that menstruation is absent), headaches, dizziness, cramps, etc., can unfortunately occur. But they don't have to, it differs with each TriXy and there is help from the doctor for almost everything, so you can get it under control.

## How to recognize TXS from the outside

- many TriXies have beautiful almond eyes, it's called epithelfalt
- epicantism is called when the eyes are a bit wider apart
- a minimal broader nose bridge can occur
- a "pinky finger" is a curved little finger (first limb)
- TriXies have a lot of potentials to have a top model figure with long limbs, often longer than average. Rapid growth during puberty occurs more often
- Muscle tone is often not optimal even as a baby, but can be compensated for with sports, exercise and occupational therapy

## What is often annoying at school and with other teenagers

- Social groups like class, sports clubs or other groups are often not TriXies' cup of tea. Girls Scouts, youth firefighters or other groups that leave no one behind and are about community and not competition are usually a better choice.
- Emotional development is sometimes about 2 years later but is usually all caught up. Everything has its time.
- Nail biting, nibbling or other repetitive movements and actions happen. It's not bad, but it often annoys others and that annoys TriXy.
- Referring a lot to oneself, feeling attacked happens often. Learn to check the situation or reaction of others, and ask in case of doubt whether the other person really meant it that way.
- Memory problems, well storing and processing information can sometimes get a bit much. Especially when there are many people around or it is noisy. Be patient, and try other ways of learning, if staring at books doesn't work, then a lot can be fixed, for example through video tutorials or apps that help with learning.
- TriXies often have a highly sensitive perception, only the processing or filtering of the information and feelings sometimes needs a little more time. Be relaxed with it, everyone has his own pace.
- TriXies sometimes find it a bit more difficult to interpret feelings or social rules and carry them out themselves. Time is your friend, the older you get, the better you will be able to understand the world. Does something seem strange to you? Then dare to ask, most people will be

happy to explain it to you again. Practice being aware of feelings in people and yourself.

- Language can be really complicated. Especially figurative language or meaning of words are sometimes difficult to understand. Ask, and let others explain to you how they understand the words. Making up meanings for yourself can often be difficult. Be curious, ask about, how others understand the words.
- Grammar, how to express yourself, pronunciation, stuttering, writing, reading (letters blur, words "dance") and the motor skills of how to hold the pen are sometimes challenging. Don't give up, practice, ask questions, and it will get better.
- Friendships, family relationships, or dealing with teachers is already quite complicated. Many TriXies have fewer friends than others, but that's not a bad thing. It's better to have one or two good friends who like you the way you are, that's more valuable than many "friends" who aren't really close to you.

## What helps to live with Triple X

- Understanding
- Information about TXS
- do not immediately target parents' education, but question syndrome, match it
- Avoiding, and questioning false diagnoses such as ADHD, dyslexia or autism
- Protect TriXy from the scorn and hostility of classmates, and support TriXy to be accepted in the class, otherwise withdrawal, blocking, non-participation, drop in grades or self-harm often follows
- Patience, e.g. other learning methods (e.g. audio and video instead of paper), repetition
- no reproaches, "you must know that, we already had that".
- more breaks
- no punishments, emphasis on good successes, positive feedback, focus on good points and qualities
- Perception of the TriXy's perception and perspective
- Compensations for disadvantages, support measures such as learning time extension (like autistic or ADHD), school assistance, IEP
- Strategies and assistance for structured learning and management of tasks (checklists, timers, reminders), Trixies will not be able to do this easily on their own.
- Explanation (different or repeated) of the questions if needed
- Take exams and tests under quiet conditions
- retreats, quiet rooms, quiet times
- other forms of presentation, e.g. for papers or lectures (video, individual lecture with the teacher, compensation key for faulty performance, e.g. stuttering, spelling)
- Spelling does not work, rules not memorable. Some things have to be crammed.
- For evaluation: observations in class, conversation or analysis alone with an adult is not comparable because better than in the classroom

which is noisy and restless

- Adopt and maintain a positive attitude toward TriXy, because negative default instinctively leads to compartmentalization and rejection in TriXy
- Encourage strengths, e.g., social positive behavior, help
- Educate other students about the special basic conditions of the TriXy, promote tolerance

## Acknowledgements

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More information, studies and an app can be found at <https://www.triple-x.info>.

If you would like to send us feedback on this book, please write to [feedbackbook@triple-x.info](mailto:feedbackbook@triple-x.info). We are looking forward to your mails!

We are producing this book with private funds so far. But we would be happy to be able to give the illustrators a proper appreciation of their work and also to be able to buy an ISBN number for the book and to translate it into English and Portuguese as well, because there is a great demand for this book. This costs not only time but also money. We are therefore happy about financial support - which we want to show transparently under this link, what was donated (anonymously) and what the money was used for. To do so, please go via this link: <https://www.triple-x.info/en/donate/> Thank you!

The information in this publication is based on experiences in the daily lives of many Triple X families and is not scientifically proven in detail. However, is often derived and developed from findings of internationally available scientific studies on TXS and other related syndromes (list on the group website). We have presented this book and also the app to leading scientists worldwide for review.

### *Medical Disclaimer:*

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