

22q

Through My Eyes



My Story

For teens and young adults with 22q11 deletion syndrome.

By Jordan Nanos

Edited by Andrea Shugar, MS, CGC, Cheryl Cytrynbaum
MS, CGC, Stephanie Ngo, BSc, and Huda Jirreh, BSc.



This book is dedicated to my mom, Maurizia, for her constant love and support throughout my whole life. She has always been there whenever I need her.

— Jordan

To me, beauty is about being comfortable in your own skin. It's about knowing and accepting who you are.

— Ellen Degeneres

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Thank you to my teachers, doctors, speech therapists, and everyone else who has been there to support me throughout my life. Thank you to SickKids for taking care of me all these years.

Forewords

As a pediatrician who cares for children with complex medical and developmental challenges, my role is to help my patients unlock the key to reach their highest potential. Having been involved in the care of children with 22q11 deletion syndrome at SickKids for more than 15 years, I am delighted to have Jordan's book as a resource for my patients. 22q Through My Eyes is a factual, practical and thorough resource that addresses important issues facing teens and young adults with 22q11 deletion syndrome. Jordan is to be commended on his willingness and motivation to share his personal story, challenges, and successes with other teens and young adults with 22q11DS and their families.

Through his story, Jordan teaches us that we are not alone, that there are others who have similar challenges to face - and that despite these challenges, we can succeed and have a good quality of life. Jordan's book is an invaluable resource for those with 22q11DS, their families, and others facing similar challenges. The healthcare provider-patient relationship is not one-sided. We all have a lot to learn from each other, and Jordan's book is a testament to this ideal.

— **Leona Fishman, MD, FRCPC**

Medical Director, SickKids 22q11 DS Clinic

Navigating through life for those with 22q can be a bumpy journey with significant challenges. No one understands that better than the individuals impacted with this deletion. This inspirational book helps the reader understand the issues that arise and, most importantly, it provides strategies to deal with them. Jordan's personal thoughts and willingness to share his insights will undoubtedly provide support and tools to help others with 22q succeed.

As an educational consultant who has assisted thousands of families dealing with 22q and the parent of an adult with the syndrome, I have been deeply immersed in the problems that often arise. Jordan, along with his genetic counselor, has tackled these issues in a optimistic and practical fashion that I feel will encourage others to accept themselves and find happiness in their accomplishments. This book is written from the heart and it further exemplifies why Jordan was awarded medals for courage and love. He is truly an extraordinary young man.

— **Donna Cutler-Landsman, MS**

Educational Consultant Specializing in 22q11DS



About the Author

At the time of writing this book

Jordan Nanos was an 18-year-old high school student. He was diagnosed with 22q11DS at the age of 5 and was followed in the SickKids 22q11DS Clinic from the age of 9 until he transitioned to adult care at the age of 18. Jordan has enjoyed writing since he was a young boy, and at 15, he approached his genetic counsellor about creating this book to help others with 22q11DS. After a year of writing and editing, he was thrilled to share his story. He lives in Toronto with his family and enjoys writing, dancing, caring for his pets, and making new friends.

Jordan Today

As of October 2025



Now 26 years old, Jordan is an optimistic young man who believes life is about trying your best and never giving up on yourself. He is part of several community support programs—such as ADDUS, ConnecABILITY, and Autism House—where he has found friendship, purpose, and connection.

Writing remains one of Jordan's greatest passions. He contributes inspirational articles to ADDUS, sharing stories that help others find hope. He also enjoys expressing himself through art and being part of inclusive spaces that celebrate people's strengths.

As Jordan says: "To be a writer you have to think like a writer."

Book Contents

Introduction	1
About This Book	2
Chapter 1: About 22q11DS—Common Questions.....	3
Chapter 2: Growing Up With 22q11DS.....	7
Chapter 3: Common Challenges—Social Skills.....	10
Chapter 4: Common Challenges—Bullying.....	12
Chapter 5: Common Challenges—Learning.....	14
Chapter 6: Common Challenges—Mental Health.....	16
Chapter 7: Common Challenges—Adulthood.....	18
Chapter 8: Common Challenges—Keeping Safe.....	20
Chapter 9: Focusing on Your Strengths.....	22
Chapter 10: Sharing My Achievements.....	24
Resources —Recommended Organizations.....	26
Resources —Teens and Young Adults.....	27
Resources —Parents.....	29
Final Thoughts	30

Introduction

My name is Jordan. At the time of writing this book, I was 18 years old. I have 22q11 deletion syndrome, but I'll call it 22q11DS from now on. I will always have 22q11DS, it's a part of who I am. This is my story of growing up with 22q11DS and how it has shaped my life.



Me when I was five years old

In this book, I share my experience with 22q11DS and some of the common challenges that often come with it. I share how these challenges have affected me personally. It can be hard to accept the things that are difficult in life, but it's important to face them.

I wrote this book to make a difference in the world, and in the lives of others living with 22q11DS. By telling my story, I want other kids with 22q11DS to know that they're not alone. I want to encourage them to see not only their challenges, but also their strengths and find ways to cope. Most of all, I want them to feel proud of who they are, and hopeful about what they can achieve.



Me as a baby

About This Book

This book is divided into 10 chapters.

Chapter 1 gives an overview of 22q11DS.

Chapter 2 introduces me and shares what it was like growing up with 22q11DS.

Chapters 3-8 focus on common challenges people with 22q11DS face, like social skills, bullying, learning, mental health, adulthood, and staying safe.

Each of these chapters is divided into three sections:

“Through my eyes” - where I share my personal experiences.

“A note from the genetic counsellor” - where my genetic counsellor explains how some of these challenges can affect people with 22q11DS.

“Strategies” - where I share tips that have helped me and might help you too.

Chapters 9-10 wrap up with my reflections on the importance of recognizing your strengths and celebrating your achievements.

At the end of each chapter, you'll find a link to a resource we think is especially helpful and relevant to that chapters' topic.

A more comprehensive list of resources and supports can be found at the end of the book.

If you read something in this book that worries or upsets you, it's important to talk to someone you trust, like a parent, genetic counsellor, or doctor. Remember, not everything in this book will apply to you.



My school photo

Chapter 1: About 22q11DS—Common Questions

What is 22q11DS?

22q11 deletion syndrome (22q11DS) is a genetic condition that affects about 1 in 2,000 children. People with 22q11DS are missing a small piece of their 22nd chromosome. You may also hear it called Velo-cardio-facial syndrome or DiGeorge syndrome. They are all different ways of describing the same condition.

Some people with 22q11DS have many medical challenges, while others have very few or none. 22q11DS can also affect how a person learns. The most common features seen in children with 22q11DS are listed below. Everyone is different, and some may have more or fewer of these features.

Other possible features include kidney differences, changes in how the thyroid gland works, hearing loss, and dental cavities. As people with 22q11DS get older, some health issues may improve (like a stronger immune system), while others may appear later in life, such as low calcium or mental health concerns.

Some common features of 22q11DS:



Low Calcium (Hypocalcemia)

If not treated can lead to:

- Tremors or seizures
- Weak or fragile bones

Palate and Speech Differences

- Cleft palate
- Velopharyngeal insufficiency (VPI)
- Nasal-sounding speech

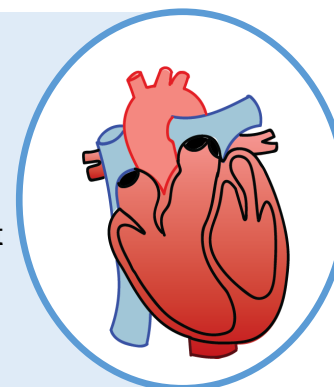


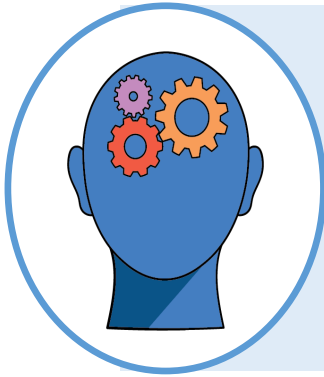
Weaker Immune System

- Frequent infections in early childhood
- Possible reaction to live vaccines

Heart Defect

- A hole in the heart (VSD, ASD)
- A more complex heart problem (Tetralogy of Fallot or Interrupted Aortic Arch)





Mental Health

- Anxiety, ADHD, autism spectrum in childhood
- Anxiety, psychosis, or depression in adulthood

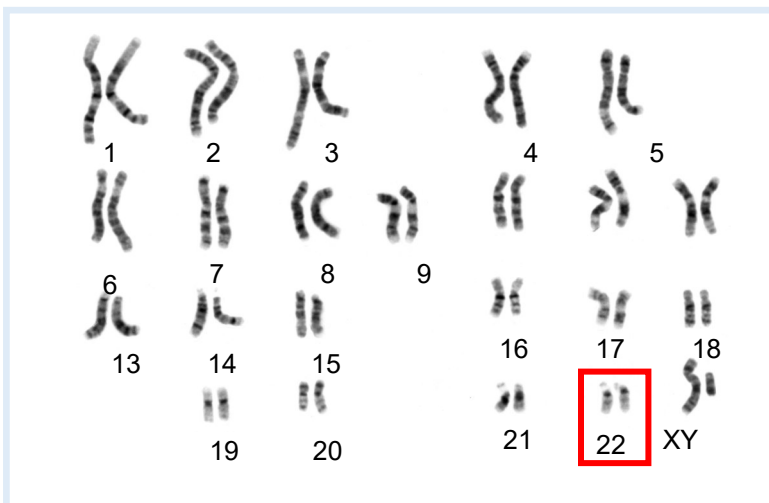
Learning Difficulties

- Learning disability
- Intellectual disability
- Slow learner



What are chromosomes, anyway?

Our bodies are made of billions of cells. If you looked at one of your cells under a microscope, you would see chromosomes, like in the picture below. We each have 23 pairs. The small ones in the red box are the 22nd pair.



A picture of human chromosomes

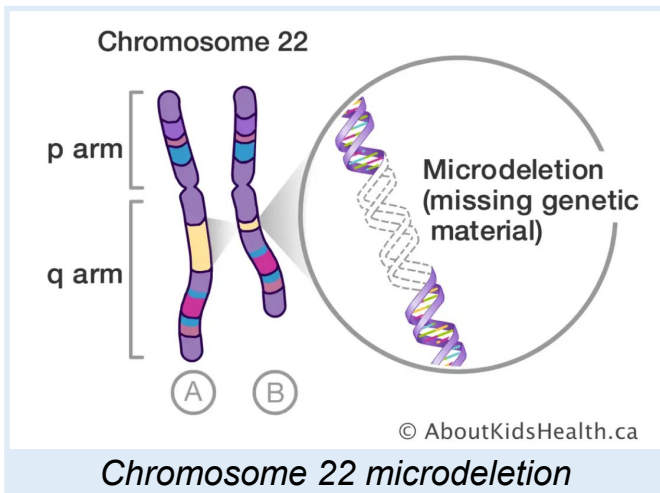
A person with 22q11DS has one complete chromosome 22 and one missing a small piece. This missing piece is called a *micro-deletion*.

Chromosomes are like an instruction manual for how the body grows and works. Even though it's tiny, this missing piece can affect how the body develops and functions.

Everyone with 22q11DS is affected differently. In my case, it has impacted my learning, speech, mental health, calcium levels, and immune system.

– Jordan





The microdeletion is like a missing page in a recipe book—the instructions aren't complete.

Being born with a chromosome microdeletion can cause health and/or developmental challenges, such as learning or behavioural differences.

How can genetic counselling help?

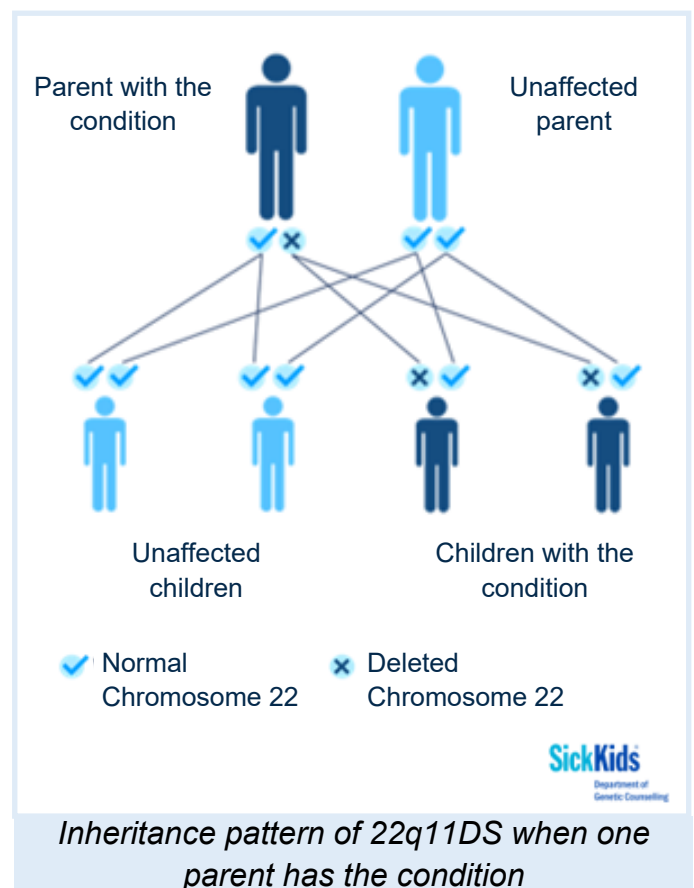
A genetic counsellor is a health professional who understands genetic conditions and how they affect people. These are some of the ways they can help you:

- Learn more about your condition, how it's inherited, and how it may be passed on
- Cope with the emotional challenges that can come with having a genetic condition
- Explore your options for having children in the future
- Find support for your medical and mental health needs

If I have my own children, will they have 22q11DS?

We get half of our chromosomes from our mom and half from our dad. When we have children, we also pass along half of our chromosomes to them. Some people with 22q11DS go on to have their own children. A person with 22q11DS has a 50% chance of passing on their microdeletion.

In other words, there is an equal chance of having a child with or without 22q11DS. The image on the right shows what this might look like if one parent has 22q11DS.



How do I stay healthy with 22q11DS?

Although there is no cure for 22q11DS, it's important to take care of your health and manage any medical issues that come up.

Make sure to visit your doctor and health care team regularly, and let them know if you have any medical or mental health concerns. Learn how to advocate for yourself. This means speaking up, and asking questions, and getting the information you need.

To stay healthy, it's recommended that you:

- Have annual bloodwork done – to check your calcium, thyroid, and platelet levels
- Eat healthy with a focus on calcium and vitamin D rich foods
- Make sure to exercise regularly
- Get immunized (if your doctor says it's safe) for HPV, chicken pox and other common viruses
- Limit sugary and caffeinated drinks, avoid recreational drugs (like marijuana) and alcohol

Calcium and **vitamin D** play an important role in keeping your bones and muscles strong. Calcium helps build and protect your bones, while vitamin D helps your body absorb calcium. Together, they keep your body healthy and working well.

If you're not getting enough through food or sunlight, your doctor may recommend you take a supplement.



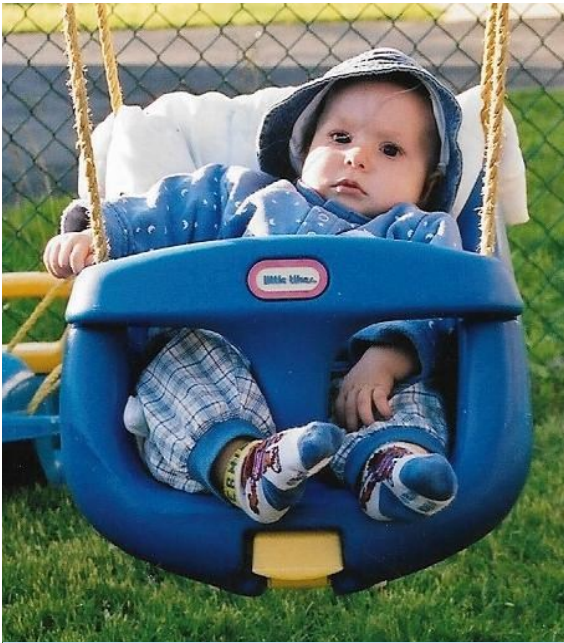
For more information and a list of calcium, and vitamin D rich foods visit:

[About Kids Health: Bone Health](#)

Recommended Resource: [SickKids 22q11DS Clinic](#)



Chapter 2: Growing Up With 22q11DS



Me as a baby

Growing up with 22q11DS was difficult at times. As a baby, I hardly made a sound and was always quiet. I had trouble speaking, so I would point to things when I didn't know how to say what I wanted. My parents could tell something wasn't quite right.

When I was 5, they took me to the doctor for some tests. The doctor told my parents that I had 22q11DS. My parents were really calm when they heard the diagnosis. They told me that this was just a part of who I am, and that I would always be their son, with or without a disability.

Since then, I've come a long way with my speech. My mom took me to a speech pathologist, and she practiced with me every night when I had trouble sounding out words. She believed I could do it, and I'm so glad she did.

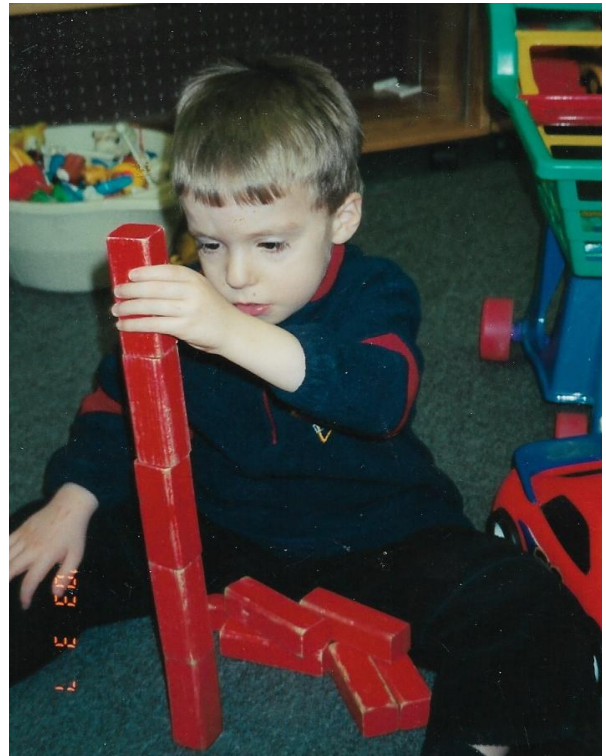
At first, I didn't like having 22q11DS. I faced challenges like bullying and social anxiety, but as I got older, I realized that this is a part of who I am, and learned to accept it.



Me at my speech class. I got a sticker every time I did something well.

That acceptance made me feel lighter and more confident. I even began sharing my diagnosis with friends. In high school, when I finally told them, they accepted me for who I was, and that's how I knew they were my true friends.

I believe that, no matter what disability you have, you're just as capable as anyone else. You just need to believe in yourself. Everyone deserves to go after what they want in life. People should be treated the same, disability or not. Everyone deserve to work, have a home, be successful, and be treated with kindness and respect.



Me in preschool

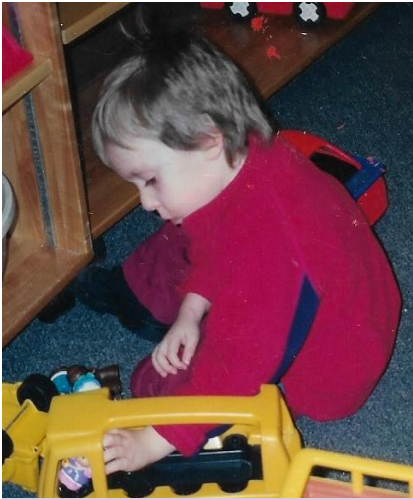


Me in grade 2

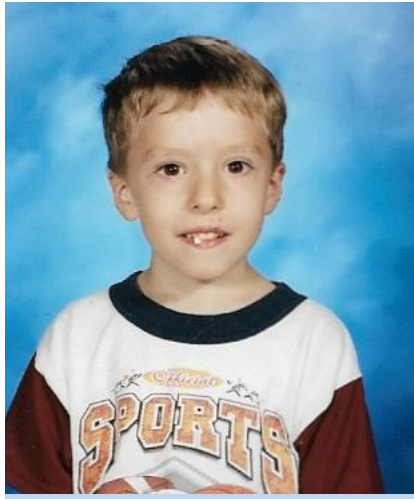
Even though I have 22q11DS, I'm an independent person who can do a lot on my own, but I also reach out for support when I need it. Over the years I've had help from my speech pathologist, occupational therapist, ENT doctor, family doctor, teachers, genetic counsellor, and psychiatrist for anxiety.

I know it can be scary to ask for help. It might feel uncomfortable, but it's completely normal, and we all need it sometimes.

The best advice I can give to others living with 22q11DS is simple: be yourself, and you'll find people who will accept you just the way you are.



Preschool



Kindergarten



Grade 1



*Vacation in Honey
Harbour, Ontario*



*Me wearing my favourite
jacket*



My 6th Birthday



Me at 18 years old



What I look like today

Chapter 3: Common Challenges—Social Skills

Social skills are our ability to interact with others in a positive way. They help us make friends and good judgments about people and situations.



Through My Eyes

When I first started school, it was hard to approach other kids. I didn't know what to say, and starting conversations made me anxious.

Over the years, I've gotten better at talking to people because I've become more confident. I can still be shy or awkward sometimes, but that's okay. What matters is trying. If you make a friend, that's great! And if you don't, that's okay too. You should be proud of yourself for the effort .

It's not about how many friends you have, but about having at least one good friend who treats you well and accepts you for who you are.

I was 16 when I told my first friend that I had 22q11DS. Before that, I was scared they wouldn't accept me, but I knew it was the right time. I wanted to be honest because this is such a big part of my life.

The first friend I told was really supportive, which gave me the confidence to tell the rest. I chose to share it with friends I trusted, people who respected me. Everyone was surprised because they had no idea, but I explained what 22q11DS was and how it affects me.

After that, all of my friends told me that I was still the same Jordan, and that I was still their friend. That was such a relief and it gave me hope for others with 22q11DS. You don't need to be afraid to tell your friends. Once they understand, they might treat you with even more kindness and understanding.

My social skills have really improved since I was a kid, thanks to some strategies I've learned over time. One of the biggest helps was my mom. She taught me what's appropriate to say, when to say it, and who to say it to.

For example, some stories are fine to share with friends or family, but not with teachers or people you don't know well. It all depends on the relationship, the situation, and what you're sharing. My mom practiced this with me and gave me advice that I could follow.

Social Skills and 22q11DS – *A note from the genetic counsellor*

Having trouble with social skills may look different for everyone. Here are some common challenges that people with 22q11DS may face:

Making and maintaining conversation: It can be harder to express your thoughts in words, or to know how to start and keep a conversation going. This can sometimes leave you feeling frustrated, misunderstood or left out.

Social cues and boundaries: It may be hard to understand unspoken 'rules' like how much to talk, how close to stand, and how much to share with different people. Some may also

find it hard to judge if a person is being friendly out of kindness or because they want to take advantage of you.

Shyness and self-consciousness: You may feel shy, self conscious, or even scared in large groups or when meeting new people. This can lead to social anxiety and make you want to avoid social situations.

Sometimes these challenges are due to a condition called autism spectrum disorder. The important thing to remember is that social skills, just like any skill, will get better with practice and guidance!

Strategies to Help with Social Skills



Stay positive and never give up. You never know when you might find kindness in someone.

Be confident and open to talking with new people. You can start the conversation and decide if you feel comfortable. Be yourself, and people will like you for who you are.

Find people with common interests. You can meet other people through organized activities like dance class, art class, or team sports.

Share your thoughts and feelings. Talk to someone you trust who can give good advice and support.

Practice your social skills. Ask parents or teachers to help you connect with others. Join a social skills group in your school or community (like Best Buddies), or work with a social skills coach.

Recommended Resource: [Best Buddies Canada](#)



Chapter 4: Common Challenges—Bullying

Bullying is when someone makes fun of you, leaves you out, or when a group of people targets you. Bullies often do this to get a reaction or attention from others.

There are four main types of bullying:

1. **Verbal bullying** - saying or writing mean things like name-calling, teasing, or using hurtful words.
 2. **Social bullying** - hurting someone's reputation or relationships like spreading rumors.
 3. **Physical bullying** - harming a person's body or belongings, such as hitting, making rude gestures, or breaking their things.
 4. **Cyberbullying** - using the internet or social media to post mean or untrue things about someone, or to embarrass them online.
-



Making friends at school was hard for me because I was bullied. Other kids made fun of the way I looked, mocked my voice for sounding nasally, and always picked me last in gym class. Sometimes, they acted like I wasn't even there. Whenever I tried being kind to one of them, they would just ignore me.

Through My Eyes

What they did was hurtful, but I've learned that there was no reason for me to be treated that way. They were doing it to get a reaction out of me. Being bullied can make you feel scared, sad, or angry, but standing up for yourself can help you grow stronger and more confident.

One way I dealt with bullying was through dancing. When I dance, it's hard to describe exactly how I feel, but the energy in the room feels amazing. It helps me release my emotions and feel so much better.

Bullying and 22q11DS – A note from the genetic counsellor

No one deserves to be bullied. Unfortunately, it happens more often to kids who are seen as “different”. But that doesn’t make it right. Bullying hurts, and it’s important to remember: it is never your fault.

You have the right to feel safe, whether at school, at work, at home or out in public.

If you are being bullied, talk to someone you trust (like a parent, grandparent, or teacher). Let them know what happened, who was involved, and what you’ve already done in response.

When you tell someone about your experience, you should expect:

- To be listened to
- To be taken seriously. Your concerns should not be dismissed
- Your privacy (confidentiality) to be respected, if that’s important to you
- A conversation about how to respond and keep you safe
- A plan to monitor the situation moving forward

Adapted from <http://www.beyondbullying.com>

Strategies to Help with Bullying



Try not to react. Bullies want a reaction. If they don’t get one, they may lose interest.

Tell someone you trust. Like a teacher, principal, parent, or another adult. If you’re not being heard, keep speaking up until someone listens.

Stay strong and think positively. Try to stay hopeful that things will get better. Believe in yourself, you can get through this.

Help someone else. Standing up for others helps them, and can make you feel proud and strong.

Focus on passions you love. Activities like acting, dancing, or writing can help you cope and give you something positive to look forward to.

Do not believe the bully’s negative messages. Remind yourself: they’re being mean, but their words aren’t true. There are so many people who see how amazing you really

Recommended Resource: [Beyond Bullying](#)



Chapter 5: Common Challenges—Learning

Learning difficulties can include a learning disability, intellectual disability, or being a slow learner.



I am delayed by about three years in my development, which has affected how I learn. In elementary school, I noticed that I learned differently from other kids. They could do assignments on their own, but I needed extra explanations and it usually took me longer to finish, especially in Math and Language.

Through My Eyes

Because I was struggling, my mom talked to my teacher about getting me an Individualized Education Plan (IEP). An IEP lets my teachers know that I have a learning disability, so they can give me more time on tests and projects. It also means I can get one-on-one support from a teacher or tutor who understands how 22q11DS affects my learning.

As I got older, school started to feel easier. I used to get distracted a lot in class, but I realized how important school is for my future. Now, I'm better at staying focused. I still have challenges, but I'm learning to be patient with myself.

Sometimes I work really hard on an assignment and still don't get the grade I hoped for. I might not have fully understood the task, even though I took my time and tried my best. When that happens, I remind myself to keep going and do better next time. Sometimes, I ask my teacher if I can redo the assignment. It's important to speak up and ask for help. We all need extra support sometimes, and there's nothing wrong with that.

Over the years, I have gotten better at working independently. I don't need as much help as I used to, and believing in myself has made a big difference.

Learning Difficulties and 22q11DS – A note from the genetic counsellor

Many students with 22q11DS may find learning tasks challenging, such as math, problem-solving, and reading comprehension. They may also have difficulties with working memory (remembering instructions to complete a task) and executive functioning (organizing and planning tasks).

An Individualized Education Plan (IEP) can be very helpful. An IEP tells your teacher how you learn best and what supports you may need in the classroom. It is important to get schoolwork that is not too hard and not too easy, but is just the right challenge for you.

Most high schools offer different levels of classes such as Academic, Applied, Locally Developed, and Life Skills. Many students with 22q11DS will take classes from more than one of these levels, depending on their learning needs and strengths.

Everyone with 22q11DS has their own unique abilities. Being a hard worker, following through on assignments, being kind and cooperative, or having a special talent or skill (like drawing) can all help you be successful, even if learning is difficult.



Strategies to Help with Learning Difficulties

Stay focused on your work and avoid distractions. If noise makes it hard to concentrate, find a quiet space at home or ask to write tests and assignments in a separate room at school.

Use reminders to stay organized. If you have trouble with working memory, to-do lists, calendars, or planners can help track assignments and test dates.

Ask for extra help when you need it. A tutor or one-on-one support from a teacher can make a big difference. Written notes, or breaking questions into smaller steps can also help.

Focus on your own progress. Don't compare yourself to other students. Instead, look at how far you've come and celebrate the improvements you've made over time.

Be your own advocate. Practice explaining how 22q11DS affects your learning so you feel confident asking for the support you need.

Recommended Resource: [Smart Kids with LD](#)



Chapter 6: Common Challenges—Mental Health

Just like our bodies, our minds are an important part of our overall health. Having good **mental health** means being able to handle the normal stresses of life. People with good mental health still feel emotions like sadness, anger, and fear, but they can cope with them in healthy ways.



Through My Eyes

I started having mental health challenges in high school. I have anxiety and a condition called OCD, which stands for obsessive-compulsive disorder.

Because of my OCD, I used to wash my hands a lot to feel clean. I also struggled with counting, especially when it came to odd numbers. For example, if I touched something three times, I would feel anxious until I touched it again to make it an even number. I only felt comfortable and in control with even numbers.

Sometimes I also have panic attacks, where I get nervous and overwhelmed by things that scare me like spiders, thoughts of violence, or worries about the future. During a panic attack, I feel shaky, clammy, and nervous. My lips get dry, my skin feels heavy and tingly, and my chest feels like quicksand.

When that happens, I try to calm myself down by taking deep breaths, drinking water, and listening to music. I also try to focus on happy thoughts until the anxiety eases.

I have a doctor (called a psychiatrist) who helps me deal with my anxiety, and I take medication. I also get a lot of love and support from my mom, which makes me feel safe and cared for.

Mental Health and 22q11DS – A note from the genetic counsellor

Some (but not all) people with 22q11DS may experience a mental health challenge at some point in their life. In children and teens with 22q11DS, common conditions include attention deficit and hyperactivity disorder (ADHD), autism spectrum disorder, and anxiety disorders. In adults with 22q11DS, depression, anxiety disorders, and psychotic disorders (sometimes this can be schizophrenia) are common.

Every now and then, take a moment to reflect on the mental health checklist on the right. If you notice one or more symptoms, it's important to speak to someone you trust—like your doctor, parents, teacher or counsellor. Paying attention to these signs early makes a big difference, and getting help sooner often

leads to better recovery. Keep an eye on how you're feeling, and don't be afraid to ask for help.

Mental Health Checklist

(If you can check off any of these boxes, speak to someone you trust.)

- ☐ I feel very anxious or find myself worrying a lot.
- ☐ I feel sad most days.
- ☐ I have more difficulty concentrating now.
- ☐ I don't feel I can trust people like I used to.
- ☐ I don't enjoy things anymore.
- ☐ I sleep much less or much more than before.
- ☐ I hear voices even when no one else is around.
- ☐ I don't want to get up in the morning anymore.
- ☐ I feel hopeless.

From The International 22q11.2 Foundation <http://www.22q.org>

Strategies to Help with Mental Health



Take care of your physical health. Exercise regularly, dance, play sports, eat healthy, and get enough sleep.

Avoid alcohol, drugs and caffeinated drinks. Using marijuana (pot) can increase the risk for developing schizophrenia, especially in teens and young adults.

Relax your mind. Try meditation, colouring, listening to calming music, or deep breathing.

Learn how to manage stress. Focus on what matters most to you, let go of small worries and use positive self-talk to encourage and motivate yourself.

Talk to someone you trust. Speak to an adult who cares about you. Talking to family, friends, or support groups, can really help.

Get professional help. Speak with a doctor or mental health professional **as soon as you are concerned** about your mental health.

Recommended Resource: [Mental Health Information Sheet](#)



Chapter 7: Common Challenges—Adulthood

Transitioning to adulthood means becoming more mature—being understanding, respectful, and responsible—and learning to make good decisions for yourself. This stage of life comes with new changes and challenges like living on your own, taking care of yourself, and having a job. Each person should find a level of responsibility and independence that works best for them.



When I was 16, I got my first job as a cashier. Before getting the job, I had to prepare for the interview, which was scary, but I reminded myself to stay confident and calm by focusing on my strengths. I know that I'm organized, I have a good memory, and I'm a hard worker.

Through My Eyes

Being independent can be challenging, so it is important to be prepared. My mom helped me by showing me how to travel to work a few times until I felt ready to go alone. I also had a plan in case something went wrong, like getting lost, and I knew I could always call home for help.

Even though I was nervous about starting the job, I was also excited. Having a job gave me something meaningful to do in my spare time, and I wanted the responsibility of making my own decisions. Taking on responsibility teaches you how to take care for yourself and others, and I enjoyed that. As you grow older, you learn more and gain experience. With that, you can support others who are just starting out.

In the future, I look forward to graduating from high school and going to college. I have many dreams: becoming an author, actor, dancer, dance teacher, and businessman. I know that as I get older, I'll find the right path for me.

No matter what challenges you face in life, disability or not, everyone has the right to work and deserves to be treated with respect.

Transitioning to Adulthood and 22q11DS – A note from the genetic counsellor

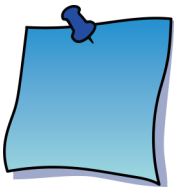
Transitioning to adulthood is a process, not just a single event. Every stage of childhood is a chance to build independence. It can be hard for parents to step back, but it is important for kids to take on more responsibility as they grow. Transition should start early in childhood.

We all need support, even as adults. The goal is to find the level of independence that feels safe and fulfilling for you. For some, this might mean living on your own,

starting a family, or having a job, etc. For others, it may mean living in a more supported environment and getting help with certain things, like managing a budget.

Think about your goals for independence and talk about them with your parents, teachers or mentors. Work together to create a plan towards your goal one step at a time. Ask yourself, “Is this realistic? What support will I need to reach my goal?”

Strategies to Help with Transitioning to Adulthood



Practice doing things on your own. Try traveling to school, buying something at a store, ordering food, or making a meal. It may feel scary at first, but the more you practice, the more confident and independent you'll feel.

Take on responsibility. Start with chores at home like laundry, setting the table, cleaning, or caring for pets. You can take it a step further by joining a co-op program at school, getting a part-time job, or volunteering in your community.

Find healthy ways to handle the stress. Change can feel overwhelming. Focusing on things in your life that make you happy and that are not changing, this can help keep you calm and grounded.

Talk to a trusted adult. Having someone you can go to for advice, comfort, and support, like a teacher, counsellor, or family member can make a big difference as you navigate becoming an adult.

Recommended Resource: [ConnectABILITY](#)



Chapter 8: Common Challenges—Keeping Safe

As we get older, we gain more independence and have more opportunities to make our own decisions. While we can't always control when something bad happens, we can often avoid tricky situations, some of which may be unsafe.

Unfortunately, people with disabilities are more likely to be taken advantage of. That can feel scary to think about, but the more you understand how to stay safe, the less likely you are to be exploited. (Being exploited means someone is using you unfairly or for their own benefit.)

The first step in **keeping safe** is knowing the types of tricky situations you might face as a young adult. Once you're aware, you can learn how to avoid them and minimize your risk. In this chapter, we will look at four important areas: online and internet safety, money and spending, relationships, and physical safety. If you ever find yourself in an unsafe situation, don't be embarrassed to tell someone you trust and ask for help. It can happen to anyone. What matters most is getting support and removing yourself from the situation.



I have been lucky because I haven't faced tricky situations myself. My mom has always looked out for me. She taught me to be careful about who I talk to, to never share personal information online, and to watch out for people who ask for too many favours, expect me to buy things for them, or try to take advantage of me.

Through My Eyes

These situations can be hard, especially if saying “no” feels uncomfortable. For example, if a friend asks for money, you might worry that they'll be upset if you refuse. But it's important to remember that your needs matter too. I used to struggle with this until I asked myself, “What's the worst that could happen?” I realized that if someone stops being your friend just because you said no, they were never a real friend in the first place.

Strategies to Help with Keeping Safe



Internet

- Be careful who you trust online, and never share personal information (like your full name, phone number, or address) with strangers.
- Adjust your privacy settings so only people you know can view your posts.
- Remember to keep your passwords private.
- Don't do anything online that you wouldn't do in real life, like bullying or gossiping.
- If being online starts to make you feel sad, anxious, or distracted, it's okay to take a break. You're in control—block or unfollow people who make you uncomfortable, or even delete accounts if it helps your mental health.

Money

- Keep track of your money. Some friends may ask to borrow it and not pay you back. Practice saying no so you feel confident standing up for yourself.
- Be careful of online and phone scams. If something feels suspicious, it probably is. It's okay to just hang up or log off.
- Don't show money or valuables in public, as it makes you more vulnerable to theft.

Relationships

- Set clear boundaries with friends.
- Ask yourself, "Is this relationship healthy?" A healthy relationship includes honesty, respect, trust, equality, and feeling comfortable being yourself.
- Avoid peer pressure—you don't have to do anything just because someone else is.
- Sexual safety means more than preventing sexually transmitted infections (STIs) or pregnancy. It also means feeling safe, respected, and secure with your partner.

Physical Safety

- Make sure someone you trust knows where you are and when you'll be home.
- Try your best to come home on time.
- Avoid going to unsafe places, like dangerous areas, or parties with people you don't know.

Recommended Resource: [Holland Bloorview Tip Sheet](#)



Chapter 9: Focusing on Your Strengths



Even though I have faced a lot of challenges in my life, I am really proud of how far I've come. When you're struggling, it helps to focus on your strengths. Don't forget how amazing you are—you can do anything.

In the past, I had a hard time feeling confident. I let my fears get in the way of what I wanted to do. For example, when I had a school presentation, I worried that my classmates would laugh at how I looked or talked. I overcame that fear by learning not to care so much about what other people think and by believing in myself a little more each time.

When you're confident and happy with who you are, it becomes easier to ignore other people's opinions. Over time, I got more involved in presentations, and now I can even do public speaking in front of large groups.

To build my strengths and confidence, I focused on the things I enjoy and do well. I've always loved writing, and when realized I was good at it, I shared that with my genetic counsellor, Andrea. She encouraged me to write a book about my experiences growing up with 22q11DS. That's how this book came to be—I wanted to show others with 22q11DS that it's possible to do great things when you try. Being proud of yourself gives you the faith and hope to keep working hard.

Having positive thoughts is a big part of taking care of yourself and staying healthy. I focus on the positive by doing things that make me happy and letting go of what others think. I also schedule time in my day for things I enjoy, so I have something to look forward to.

I encourage everyone to take some time to reflect on what they're good at and what brings them joy.

– Jordan



Take a moment to appreciate your own strengths

What are you good at?

Drawing? Writing? Arts or Sports?

Cooking? Taking care of pets?

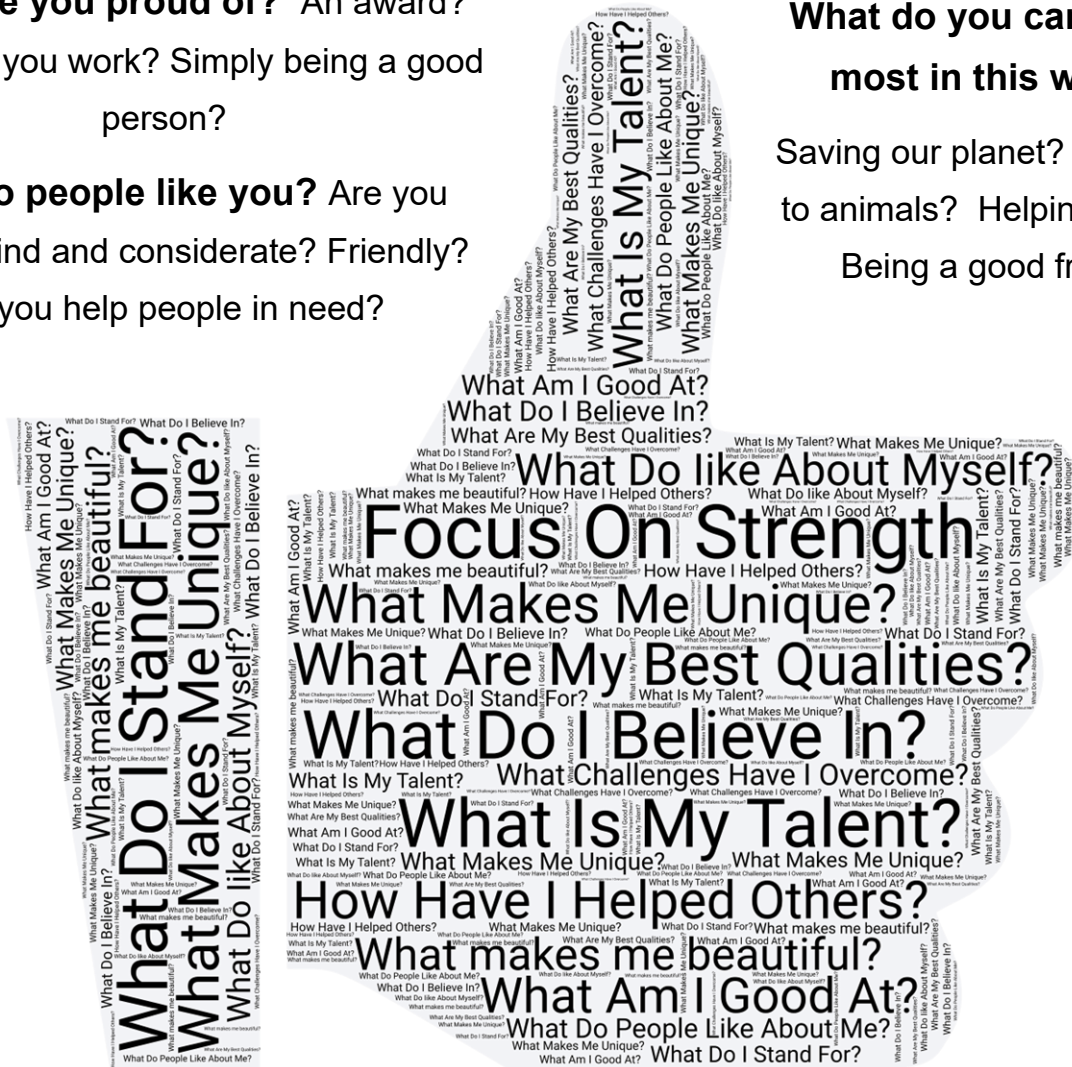
What are you proud of? An award?

How hard you work? Simply being a good person?

Why do people like you? Are you funny? Kind and considerate? Friendly? Do you help people in need?

What do you care about most in this world?

Saving our planet? Kindness to animals? Helping others? Being a good friend?



Take a look at this word cloud and spend a few minutes thinking about all of your strengths.

Ask someone who knows and cares about you to give their perspective too.

Chapter 10: Sharing My Achievements

I've worked really hard for my achievements, and I want to share a few of them with you. What are some things you've done in your life that you're proud of?

Awards

At school, I won a medal for love. My teachers nominated me as one of the top ten kindest kids in the whole school. This means a lot to me because it showed that people recognized and appreciated my kindness.

I also received an award for courage because I stand up for what I believe in.



My medal for Love



Me speaking at a conference for 22q11DS at SickKids in November 2017

Public Speaking

I like raising awareness about things that are important to me. Public speaking let's me reach many people at once, instead of just helping one person at a time.

It gives me confidence because it's something I enjoy and have worked hard to get better at. It makes me proud to see how much my confidence has grown.

Being a Good Person

Not all achievements are trophies or medals. I'm proud of being a good person—being kind and showing respect to everyone.

I also love taking care of my animals, especially my cats. Feeding and caring for them every day helps me practice responsibility too.



Me and my cat when we were younger

Writing this Book

Writing this book was hard, but it was very rewarding. It took a lot of effort to think, write, and edit everything to be clear and organized. Some stories were tough to share because they brought back difficult memories, but I reminded myself that those times are behind me, and today is a new day.

Writing this book was also fun because I enjoyed watching it all come together. This was a brand new challenge for me, and even though it took longer than I expected, I stayed committed. Sometimes I worried it would never be done, but I learned the importance of being patient, working hard, and not rushing the process.

In the end, all the extra time we spent editing this book was all worth it. I'm proud of what we created, and even more excited that it will reach so many people and hopefully make a meaningful difference in their lives.

Recommended 22q Related Organizations

The resources listed here—and those in the following pages—are not comprehensive. They include some of the key 22q-focused organizations, clinics, and community supports that we believe may be especially relevant and helpful.

Canadian Clinics and Organizations

[The Dalglish Family 22q Clinic](#)— Provides specialized care and support for adults living with 22q11DS (Toronto, Ontario).

[SickKids 22q11 Deletion Syndrome Clinic](#)— Provides specialized care and support for children and families living with 22q11DS (Toronto, Ontario).

[About Kids Health](#)— A SickKids developed resource providing an accessible overview and reliable information about 22q11DS.

International Foundations and Networks

[22q Family Foundation](#)—U.S. based nonprofit organization providing family resources, events, and community connections.

[22q11 Europe](#)—Network of organizations across 14 countries working to share information promote research, and improve care for people with 22q11DS.

[22q11 Ireland](#)—Provide support to individuals and families affected by 22q11DS through community connection, education, and advocacy.

[Chromosome 22 Central](#)—Online global community offering education and peer support for individuals with chromosome 22 differences and their families.

[International 22q11.2 Foundation](#)—Global organization supporting education, awareness, and research.

[Max Appeal](#)—U.K. based charity supporting families affected by DiGeorge Syndrome, VCFS, and 22q11DS.

Resources for Teens and Young Adults

Links By Section

Social Skills

Ability Online—[Community Building Platform](#)

Best Buddies Canada—[Provides 1-on-1 Friendship Connections](#)

Kids Help Phone—[Making Friends](#)

Nemours Teens Health—[Dealing with Schools, Jobs, and Friends](#)

Bullying

Beyond Bullying—[Resources for Young People](#)

Bullying Canada—[Information for Youth](#)

Kids Help Phone—[Bullying Information](#)

PREVNet—[Cyberbullying Tip Sheet](#)

Learning

Child Mind Institute—[Staying Organized](#)

Learning Disabilities (LD) Association of Canada—[LD Basics](#)

LD at Home—[Resources](#)

LD Online—[Kids' Stories](#)

Smart Kids with LD—[Personal Stories](#)

Mental Health

BC Children's Hospital—[Mental Health Resource Book](#)

Dalglish Family 22q Clinic—[Mental Health Information Sheet](#)

International 22q Foundation—[Mental Health Tip Sheet](#)

Kids Help Phone—[24/7 Support](#)

Kids Help Phone—[Dealing with Social Media](#)

Nemours Teens Health—[Keeping a Healthy Mind](#)

CAMH—[Understanding Your Mind](#)

Adulthood

Addus—[Community Support Programs](#)

Connectability—[Planning for Life After School](#)

Connectability—[Transition to Adulthood](#)

Developmental Services Ontario—[Local Supports and Services](#)

PLAN—[Personal Support Networks](#)

Ready, Willing, and Able—[Employment for People with Disabilities](#)

The Dalgish Family 22q Clinic—[Resources and Services](#)

Keeping Safe

Connectability—[Money and Budgeting](#)

Dalgish Family 22q Clinic—[Alcohol Information Sheet](#)

Dalgish Family 22q Clinic—[Emergency Preparedness](#)

Dalgish Family 22q Clinic—[Internet Safety](#)

Dalgish Family 22q Clinic—[Sexual Health](#)

Holland Bloorview—[Safety Resource Sheet](#)

Resources for Parents and Caregivers

22Q Family Foundation—[Frequently Asked Questions](#)

About Kids Health—[22q Information Sheet](#)

About Kids Health—[Learning Disabilities Overview](#)

BC Children's Hospital—[Mental Health Resource Book](#)

Beyond Bullying—[Resources for Parents](#)

Bullying Canada—[Information for Parents](#)

Caring for Kids—[How to Talk to your Teen](#)

Caring for Kids—[Mental Health Information](#)

Caring for Kids—[Social Media Safety](#)

Connectability—[Caregiver Training and Workshops](#)

Developmental Services Ontario—[Local Supports and Services](#)

International 22q Foundation—[Mental Health Information](#)

LD Online—[Resources for Parents](#)

Learning Disabilities Association of Ontario—[Community Chapters](#)

Ontario Caregiver Organization—[Support for Caregivers](#)

SickKids 22q11 Deletion Syndrome Clinic—[for Kids](#)

Smart Kids with LD—[Parent to Parent Advice](#)

The Dalglish Family 22q Clinic—[for Adults](#)

Understood—[Practical Strategies for Caregivers](#)

Final Thoughts



Writing this book has been an incredible journey. I wrote it with the hope of being a role model and an inspiration to others living with 22q11DS. My goal is to support people around the world who share this diagnosis and face similar challenges, by reminding them that they are not alone. I want them to know that beauty exists in everyone, from their head to their toes.

I hope this book has helped you better understand 22q11DS. For those who also have 22q11DS, I hope it made you feel a little less different and more confident in yourself. I hope it encourages you to be proud of who you are, because people will love you for it. Maybe it will even inspire you to share your own story. What does 22q11DS look like through your eyes?

After going through some hard times, I can finally see the light at the end of the tunnel—and it's beautiful.

—Jordan

Independent Playful
Accepting Curious
Loyal Gentle Trustworthy
Thoughtful Supportive Funny
Nurturing Nice Smart Reliable
Strong Responsible Listener Soft
Loveable Brave I AM MORE Mentor
Committed THAN 22Q Hopeful
Positive Special
Caring Sweet Sensitive Guide
Respectful Fearless Kind
Helpful Confident
Open Honest Mature Warm
Friendly Genuine