

HEART TO HEART

CONVERSATIONS WITH KIDS

Matilda

BY RACHELI SOFER

AGE: 10

SIBS: THREE. I'M THE OLDEST.

You wouldn't know it if you saw Matilda in action, playing her viola, in dance class, or davening at shul, but she sees the world differently than you. Matilda shares her super positive perspective with Aim!

Hi, Matilda. Tell us about yourself.

I live in Chicago. I'm in the fifth grade. I like dancing—I take classes and I'm on a dance team at a dance studio—art, and swimming. I play the viola and take lessons at school. At my school you can be in the orchestra starting in fourth grade.

I have a condition called aniridia.

How old were you when you discovered that you have aniridia?

My parents found out that I have it when I was a small baby. When I was six weeks old I was super fussy. My mother took me to the doctor, who

examined me. The pediatrician was checking my eyes and saw that my eyes weren't reflecting the light properly. She called another doctor into the room and they sent me straight to a pediatric ophthalmologist, which is a doctor who specializes in children's eyes. "There's nothing to worry about until there's something to worry about," the pediatrician told my mother before we left her office. My mother didn't think that anything was really wrong, until the pediatric ophthalmologist checked my eyes and the doctor's whole expression changed.

What is aniridia?

My eyes look different from most people's. I don't have an iris, which is the colored ring around the pupil. The iris is the muscle that contracts and dilates the pupil. What that means is that all the light goes into my eyes. You know how it feels when you go to the eye doctor and he dilates your eyes and then you go outside? That's how my eyes feel when I'm outside all the time.

I was born with aniridia. It's a very rare condition that only 1 in 50,000 to 100,000 people have.

How does aniridia affect you?

My left eye has 20/80 vision. My right



Matilda with an drawing her made for school, displayed in our local library

eye has a much higher prescription, 20/400, and that's such a big difference that the brain doesn't use my right eye so much, and so I don't have much functional vision in that eye.

There are lots of different ways this affects me. I'm a slow reader and need to use a magnifier to read everything from Lego instructions to books. I also have a hard time seeing things that are further away. For example, if I see someone coming down the block I can't tell who they are until they get much closer.

I sometimes bump into things.

Tonight I went to an after-school activity and when I came outside the building it was dark. I had to have a predetermined meeting point with my parents because otherwise I wouldn't

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be able to identify my mother's car in the dark. All cars will look the same to me and I can't really see black cars in the dark at all. In general I don't like the dark.

What's it like for you at school?

I go to public school because they have services and accommodations for me that have helped me tremendously, that I would not be able to get in a Jewish day school.

For preschool I went to a mixed classroom of typical kids and kids with vision issues. Then I switched to a regular public school where I get all kinds of accommodations to help me.

I have what's called an Orientation and Mobility teacher, who teaches

me how to use a white cane for people with vision impairments and navigate the world. I go on mini trips with her, to the stores, kosher grocery, and mall to learn how to get around. She teaches me how to use public transportation and use street signs. I use a monocular, which is a small, hand-held telescope to see things in the distance, like a street sign.

How else do they help you?

I sit in the front row and have something called a Visiobook. It's a machine that magnifies the print of any book onto a screen. All of my worksheets are enlarged to 11 x 14 [28 x 36 cm].

I also have an iPad that shows me whatever the teacher puts on the smartboard. My orchestra teacher lets me use it too.

I have lessons with a vision teacher once a week. She helps me learn how to access different tools. When I was younger she taught me how to advocate for myself and all kinds of visual terminology, like what glare, contrast, and lighting mean so I'd know the appropriate words when I need to tell someone my needs.

I recently started learning Braille as an extra tool too.

The administration is very nice to me at school. For example, there are digital clocks in the school that are blue with white coloring. One day, they changed them from white to red. I told the principal that I can't see the numbers so she immediately changed it back even though I'm the only vision student in the entire school.

I'm very proud of being Jewish. I made a power point presentation about my disability and I pointed out that I am Jewish. There are a few other Jewish kids and other frum kids in the school.

I have local frum friends from shul and I go to a program started by the organization called Upwards. It's called the Lounge and it's a place where I can hang out with other frum kids and mentors.

I'm famous in my town. I'm part of Chai Lifeline and I have lots of big sisters.

I have a tutor on Sunday mornings for Hebrew and I'm always learning with my parents too.

Are you able to travel? What about going to sleepaway camp?

Sure. I actually went with my day camp on a short sleepaway camp trial. I took my cane and flashlight with me, and after the first day or two I learned how to navigate my way around the camp.



What would you say is your biggest challenge?

Walking in different weather! Because of the glare caused by puddles I can't see so well when it's rainy and I don't want to slip and fall. I don't love using my cane outside the house.

When it's really sunny I need to walk looking down because it's too bright for me.

Walking outside during nighttime is a big challenge too.

The truth is though that if you saw me in the street you wouldn't know. I get around and I do everything. I don't let my vision stop me. It just takes a little longer for me to do things, but I'm not really different. I'm just a regular girl.

Do you have a lot of eye doctor appointments?

Yes. I go to the eye doctor every three months and when something comes up I go even more often. For example, I've had multiple surgeries for things like cataracts and glaucoma, which are common complications for people with aniridia. (A cataract is when the clear part of your eye, called the lens,

gets cloudy, like looking through a foggy window. Glaucoma is when the pressure inside the eye gets too high and can damage the nerve that connects your eye to your brain.)

Is there a treatment for aniridia?

The eye is so delicate. Baruch Hashem the technology available today is out of this world. There are apps available that can read labels for me, and audiobooks, et cetera.

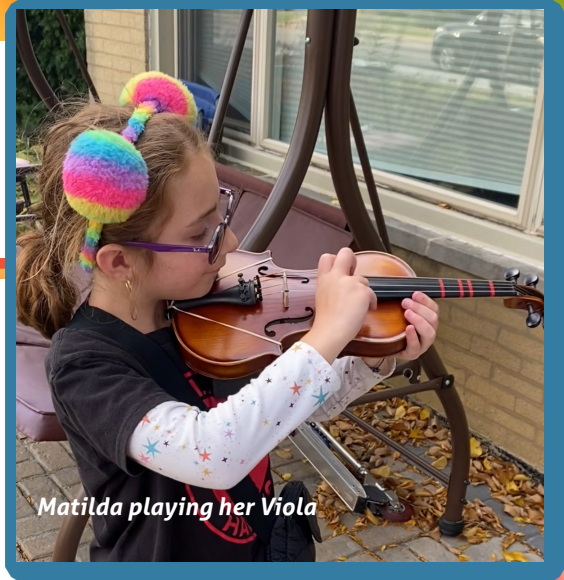
As of now there are lots of different studies going on. There are scientists studying eye transplants.

I'm not able to get an iris transplant because my right eye isn't strong enough to hold a new lens.

I might be able to get a lens with an iris for my left eye one day. I'd get to pick what color I want my eyes to be!

What color would you choose?

I think I'd go with blue because my right eye has a tiny thin circle of blue when my iris would be.



Matilda playing her Viola

about it?

If they ask. My school friends know and care. They help me carry my books and find stuff I need. I don't really discuss it with my Shabbos friends. It's just normal for me.

Sometimes they ask me why I go to public school and I tell them I see differently. I don't love answering that though because it makes me feel weird.

The truth is though that I didn't even know that the way I see is different until I was five or six. This is just life for me.

Do you have a message for anyone else with a challenge?

Stay confident. Don't doubt yourself. Keep working and stay strong.

Do you have a message for our readers?

People with disabilities are just the same so treat them the same as everyone else. You can ask them questions but don't stare. Always be kind.

There are challenges, but so many times I just forget about it. I always say that I'm not visually impaired but I have a visual impairment; it's just a piece of me.



Matilda having her eyes checked

Do you know anyone else with this condition?

We went to an aniridia convention a few years ago and met a lot of people which was nice. We've also connected to a frum family with a boy a little older than me who has aniridia, and my mother spoke to another frum woman in New York whose daughter has it too.

In general, vision impairments are rare.

Do you talk to your friends

