



# Albinism

*One family's story*

The first day of school in a new city can cause any fifth-grade boy to be nervous. But Yitzy Shain was confident that he would do fine. In his old school, he did well in class and had plenty of friends. What Yitzy did not expect was the reaction of the other boys the first time he stepped on the school bus. There were whispers, stares and a few snickers. Kids pointed at him, and when he sat himself down, the rest of the bench remained empty until he got to school. As the days passed, his schoolmates were more vocal in their teasing.

"Look, it's whitey," one boy would call out. "Hey, whitey, don't sit next to me!" yelled another.

Yitzy was aware of his extremely fair skin and white-blond hair. But he had never been singled out for his differences — until now.

Yitzy's rough start comes as no surprise to his mother, Gittel. Three out of her six children have the same pale skin and white blond hair that indicate the medical condition of oculocutaneous albinism. This congenital disorder affects the pigmentation in the skin, hair and

eyes.

Gittel herself has blond hair, and her husband's family is also light-haired and fair-skinned. When Yitzy, her second child, was born with very fair hair, she thought that it would darken over time, to become blond like hers. She had no inkling of Yitzy's condition until the birth of her third child, Kalman, two years later. Like his older brother, Kalman was extremely fair. Gittel noticed that Kalman's eyes were not focusing properly. By the age of two to three months, most babies should be able to

focus on moving objects, but Kalman's eyes shook back and forth.

"There were a few people in my family who had issues with their eyes," says Gittel. "Some of my siblings had problems with lazy eyes or crossing. I have some relatives who wore glasses at a young age or had patches." The Shains assumed that Kalman must have a similar condition, and they made an appointment to see a pediatric ophthalmologist when Kalman was five months old.

The specialist examined the baby and presented the Shains with the diagnosis of albinism. Albinism is a hereditary condition inherited from a recessive gene, which can result in the lack of pigment in the hair, skin and eyes.

The doctor warned the Shains that albinism is associated with various vision defects, including photophobia, an abnormal intolerance to light; nystagmus, involuntary eye movements resulting in limited vision, and amblyopia, lazy eye with decreased vision. In addition, the doctor cautioned that albinos are more susceptible to skin cancers, due to the lack of pigment in their skin. There is no cure for albinism, the doctor said, although one can work to manage the symptoms.

"Do you have other children with this fair complexion?" the doctor asked. That's when the Shains realized that two-year-old Yitzy might also share this diagnosis.

The doctor's diagnosis left the Shains quite frightened. Would their children ever be able to see normally? How would their condition affect the rest of their lives? In retrospect, Gittel understands that the doctor was playing it safe. "The doctor didn't know how things would turn out, so he gave us the worst-case scenario," she says.

The Shains immediately called their Rav for *hadrachah*. He advised them to be especially careful in reciting the *brachah* of *Asher Yatzar*, which refers to our healthy bodily functions. The Rav also recommended that anytime the children experienced an improvement in their symptoms, they should recite the *tefillah* of *Nishmas*.

In a shoe store later that week, Gittel noticed a family with children who were very fair. She watched them closely and re-

alized that one of the children was wearing glasses and holding the shoes close to her face in order to examine them. Gittel approached the woman and she said, "I just went to the eye doctor..."

The woman was happy to talk. She told Gittel that her daughter did have albinism, and that she functioned perfectly well. Her eyes are weaker, but otherwise she does very well in school and is happy and healthy. Coming on the heels of the gloomy diagnosis, this was a tremendous *chizuk* to the Shains.

After receiving Kalman's diagnosis, the Shains took two-year-old Yitzy to examine his eyes. The ophthalmologist said that Yitzy had albinism, and his eyes crossed occasionally. Yitzy had less pigment in his eyes, therefore his retinas were not fully developed. At that point, there was no major cause for concern. By the age of four, however, Yitzy's teacher told

the Shains that when she reads stories during circle time, Yitzy says that he cannot see the pictures.

Yitzy got glasses, but he still had difficulty with his eyes crossing. The Shains opted for surgery and Yitzy underwent strabismus surgery to correct the muscles that were controlling his eyes. Following the surgery, Yitzy wore an eye patch for several hours a day. The Shains continue to monitor Yitzy's vision, and at this point (at age twelve), although his eyes are still weak, his vision is functional.

School is a challenge for Yitzy. While he is bright and artistic, Yitzy's vision problems severely affect his academic performance. He has trouble tracking the words while reading, which is exacerbated as the print size becomes smaller. While most children adjust from the twelve-inch ABCs written on the board to the small print of *Chumash* and *Rashi*, Yitzy finds it extremely hard to focus his vision. He uses a magnifier for reading, and sits at the front and center of the classroom, so that he can see the board more easily.

Math, too, is challenging for him. "The teacher will give out a math sheet with a whole list of problems," says Gittel. "Yitzy just sees a lot of numbers and he has a hard time zeroing in on each equation." Gittel is thankful that Yitzy is a bright boy and a good thinker. As long as he knows his *milim*, he can learn



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well in *Chumash* and *Mishnayos*.

A vision specialist works with Yitzy at school, to provide him with tools to help him read more easily. He practices tracking, and works with large-print *sefarim*, if needed.

Yitzy is a sensitive child who does not like to fail. "If he thinks he can't do his schoolwork," says Gittel, "then he would rather not bother." Socially, Yitzy had always done well with his friends. After the Shains moved to a new town, Gittel realized that Yitzy was getting teased because the boys were not accustomed to his appearance. "In our old hometown, Yitzy's schoolmates knew him since he was little, and they were used to his appearance. But when the new kid shows up at school and he obviously looks different, he's going to get teased."

The Shains worked together with the school to help resolve the teasing issue. *Baruch Hashem*, Yitzy is now successfully integrated in his new school and has plenty of friends, and does as well as he can in school.

Due to his visual impairment, Kalman needs special accommodations in the classroom. Gittel makes sure that Kalman's teachers only use dark markers on the white board, and when the teacher writes on the board, Kalman will walk up to the front of the classroom in order to read it.

Kalman is an easygoing child by nature, but he gets frustrated when he reads books. Most boys in second grade are starting to read chapter books, and he does try to read with his magnifier. But it takes so much effort and concentration for him to see the words, it is hard for Kalman to enjoy the story. "His teachers tell me that he works three times as hard as the other kids, just to do his regular tasks," says Gittel.

Since he has very limited peripheral vision, it's hard for Kalman to find things around the house. When Gittel asks her son to fetch the baby's bottle, he will not see it unless it is directly in front of him.

Kalman's vision difficulties have resulted in lots of scrapes and accidents. Because of his condition, Kalman has no depth

perception, and he fell down the stairs a few times when he was younger. "I get nervous when the kids act silly or wild and start running around," Gittel admits. "I'm always afraid that Kalman is going to just run into a corner because he doesn't see it."

At summer camp, Kalman learned to swim right away. Gittel was afraid that he would get flustered without his glasses on, and she wanted to make sure that he could navigate safely in the pool. Another concern about camp is going on trips or major group activities. Because Kalman has trouble finding people in a crowd, his counselors have to keep a close eye on him.

The Shains are meticulous about exposure to the sun. Yitzy and Kalman have glasses with transitional lenses, which become sunglasses when they go outside. The children are careful to wear sunscreen to protect their skin. As the fairest child, Yitzy's skin is particularly sensitive. "He turns into a tomato if we're not careful," Gittel says. "There was a water-main break near our house and all of the kids jumped on their bikes to check out the excitement. Yitzy came back with second-degree burns because he was not wearing sunscreen."

Kalman began receiving treatment for his vision defects when he was a baby.

He wore a patch, and got glasses when he was 18 months old. When the glasses did not help his eyes crossing, he underwent strabismus surgery when he was four.

Even with his glasses on, Kalman's vision is very poor, because he suffers from nystagmus. His eyes rotate constantly and have difficulty fixing on a particular object. Kalman himself does not realize that his pupils are shaking back and forth. "He can focus his eyes more now that he is older," says Gittel. "But when he is tired, his eyes start shaking again."

In order to view objects straight on, Kalman will tilt his head sideways. "We could do surgery to center his eyes," says Gittel, "The surgery can move his line of vision to the center, so he won't have to tilt his head. But it's cosmetic only; it will

not help his vision."

The Shains are very straightforward with their children and open about their condition. "My children are not handicapped," Gittel says. "*Baruch Hashem*, they are not legally blind. They do have difficulties, which makes some activities harder for them. But we never use the word handicap in my house, and the kids do not relate to themselves as handicapped."

Kalman recently told his mother, "I don't think I could ever drive, because the sun bothers me too much and I can't see so far ahead." Gittel responded that there are many people who don't drive, for lots of different reasons.

"Kalman functions well in most other areas," Gittel says. "We never made an issue out of his visual impairment, and he doesn't feel different than the other kids."

Gittel does have one regret: that her family pediatrician did not warn her about the condition when Yitzy was a baby. The Shains moved to a different city shortly afterwards, and their new pediatrician was very helpful. Gittel never went back to her old doctor, but she wishes that he would have alerted them to the possibilities.

"This child was obviously different; his hair was white. I wish the doctor would have told me that he could be missing pigment and I should get him checked out right away." Gittel says that it's not a big deal; she wouldn't have wanted the doctor to make a fuss, but she would have appreciated a warning to be on the lookout for any problems.

"It was very upsetting for me that I did not find out anything was wrong with Yitzy until Kalman was born. Yitzy ended up having difficulty learning his letters, and we held him back a grade. If we would have known about his vision problems, we could have given him tools to learn much earlier on."

When the Shains' sixth child was born with extremely light skin and hair, they were prepared to deal with the challenges. Yitzy and Kalman Shain were delighted with the new addition. "She looks just like us," they cheered when they first saw her.

Although the condition of albinism affects people in many ethnic groups all across the world, it is very rare; an estimated one in 20,000 people worldwide are born with albinism. There are currently no studies on the occurrence of albinism within the Jewish population.

However, Gittel knows a few families with albino children.

"It's possible that I'm more attuned to noticing it, because of my own experience," she says. "Other people may think the child is very fair, but I can tell the difference."

Gittel says that some people are very sensitive to the use of the word albinism. Families may worry about the stigma of genetic disorders or may suffer from fear of the unknown. Gittel is more open about her children. "If you know anything about albinism, it's obvious that my children have it," she says, matter-of-factly.

Rabbi Shain was shopping with the children in the grocery store when a man very tentatively stopped to question him. "Is it all right if I ask you... are your children albino?" Rabbi Shain answered in the affirmative. The man told him that he had recently had a child diagnosed with albinism and asked if his wife could speak to the Shains about it.

Gittel is happy to share her experiences with others. "Many people do not even realize that my kids have a condition, they just think that they are very blond," Gittel says. "If I mention that it's albinism, sometimes people will say, 'Really? But it's so pretty!'"

The doctors have also assured the Shains that although albinism is a gene mutation, it does not get worse over time, or with future generations. Kalman's children may be albino, just like him, depending on his wife's genetic material. But they will not suffer any worse problems than he does.

Gittel does think about her children's futures, and how they will manage as adults. "We've accepted the reality and we try to deal with it," she says.

This pragmatic attitude has also allowed the Shain children to handle their condition without getting discouraged. Gittel does worry about *shidduchim* occasionally, but she reminds herself that Hashem runs the world and He is *mezaveg zivugim*.

"Of course we could make it into an emotional issue," Gittel says, "if we start talking about how hard it is for them, or how we feel so bad for them. But we try to help them as much as possible, and then to treat them just like we do all of our children." **B**

\*Names and identifying details have been changed.

Editor's Note: This feature is a recounting of one person's unique triumph over a severe challenge. All medical information is specific to this one case and in no way reflects the general progress of this disease.



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