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“We are all different.”

Raising my blind daughter

The doctors could save the life of our micro preemie, but they couldn't save her vision.

BY ESTHER MARKOWITZ

The doctor sat us down. “There's nothing more I can do for your baby,” he said. “Your daughter is blind.”

Hindy was born at NYU Medical Center on a blustery Friday night in December 2002, after a complicated pregnancy. She was born in the 24th week of gestation and weighed 750 grams (roughly one pound ten ounces). We quickly learned that “micro preemies”—those weighing less than 1,000 grams—have only a 50 to 80 percent chance of survival and are usually left with significant disabilities. My husband urged me to recuperate from my Cesarean while he grappled with the medical dilemma that was now named Yocheved Yittel Hinda.

The first time I saw Hindy, I was too scared to really look. I quickly and tearfully wheeled myself out of the NICU and back to bed. The doctors were optimistic. They said we had three factors in our favor: I had been given steroids during my pregnancy, Hindy weighed a “whopping” 750 grams, and she was a girl. Girls are stronger fighters than boys.

The next few weeks were grueling. We suddenly found ourselves in a darkened tunnel with no visible light at the end. We were strung between hope and despair, every beep of the machines affirming Hindy's fight to survive. She emerged victorious.

Nonetheless, her challenges were far from over. The ophthalmologist who came around each week to examine her eyes told us that it's common for premature babies with low birth weight to develop retinopathy of prematurity, or ROP. The retina is the light-sensitive inner layer of the eye that's connected to the brain by the optic nerve. In infants born prematurely, the blood vessels that supply the retinas are not yet completely developed. Although blood vessel growth continues after birth, these vessels can sometimes develop in an abnormal, disorganized pattern, resulting in ROP. In some affected infants, the changes associated with ROP subside spontaneously. In others, however, they can lead to bleeding, scarring of the retina, retinal detachment and loss of vision. Even in cases where ROP regresses spontaneously, these children still have an increased risk of certain eye abnormalities, including nearsightedness, misalignment of the eyes or future retinal detachment.

In order to undergo surgery, Hindy needed to be at stage IV of ROP; she was at stage III. (Stage V means that the retina has detached completely.) At that time NYU didn't have a retina specialist, so we had to transfer her to Columbia-Presbyterian Babies Hospital further uptown. When we arrived at Columbia, the doctor informed us that he was ready to perform laser surgery. He warned us, though, that sometimes the eyes don't respond and that traditional surgery becomes necessary, but it is not always effective. In fact, only 50% of those who have traditional surgery retain their vision. I remember listening with half an ear as the doctor enumerated all the risks, thinking, ‘You have to say these things in order to protect yourself from a malpractice suit. Nothing is going to go wrong. All of the other dire predictions didn't come to pass, and neither will these.’

I later learned that having the best retina specialist perform laser surgery is crucial since it can mean the difference between the patient seeing and being blind forever. Once traditional surgery has to be performed, the success rate falls significantly.

On Pesach, our phone rang. It was the neonatologist, who left us a message that Hindy would have to undergo traditional surgery. Unfortunately, scar tissue had spread to the point where additional intervention was necessary. What little light there was at the end of the tunnel had dimmed. I cried like I'd never cried before. I couldn't calm down, despite my husband's best efforts to soothe me. While his bitachon seemed rock-solid, the reality was too much for me.

Hindy's surgery was scheduled for Erev Shvi'i shel Pesach. When I handed my baby over to the nurses, I felt like I was giving them my heart. This operation would be a game changer. When he emerged from the operating room, the doctor was pretty optimistic. He had removed 80 percent of the scar tissue and was hoping for the best. Hindy's eyes were covered, and she looked small and pathetic. We were reluctant to leave, but we had to go home to be with our other children and get ready for Yom Tov.

Our hopes were soon dashed. The scar tissue grew back and pulled on the retina, detaching it. Hindy had several more surgeries. At one point the scar tissue tore a hole in the retina that was impossible to repair. Each time she went into the operating room, we were hopeful, but her eyes kept reacting in the same way. Eventually the surgeon told us that further surgery would not be justified.

Still, we refused to give up hope. We traveled to Detroit to see a world-renowned retina specialist for a second opinion. He performed several additional surgeries. But it was not to be; there was nothing else to be done. Hindy would remain in darkness for the rest of her life. With time, though, we realized that even in the deepest darkness there is light. As the Reb Nachman of Breslov explained on the pasuk "Va'anochi haster astir panai bayom hahu, and I will hide My face on that day," even when there is a double concealment, Hashem is always there.

As devastating as the news was, it also gave us room to grieve and come to terms with our new reality. For two weeks I could do nothing but cry. I was angry. I felt punished. I felt guilty. I was an emotional mess. Ultimately, however, I came to the realization that accepting the situation took all my anxiety away. "Hashem gave me this daughter, and He will give me the strength to raise her," I said. We resolved to do everything in our power to help Hindy grow into a happy, successful adult.

Hindy was discharged from the NICU five months after she was born. We took her in our arms and felt in turn that we were being held by Hakadosh Baruch Hu. With the kindness of the many people who helped us along the way, some of the darkness began to dissipate.

When she first emerged from the hospital, she was traumatized by touch. Touch meant surgery, incisions, pricking and other invasive procedures. Each time someone tried to touch her, she screamed. Hashem sent us an amazing occupational therapist who was also a massage therapist. She spent the first few sessions massaging Hindy to help her become comfortable with touch.

Her siblings were wildly excited about her. When Hindy was first born, I didn't tell them they had a new sister; that's how tenuous her hold was on life. As her survival became more of a certainty, however, they davened for her right along with us. Hindy was born when the youngest of my seven children was almost six years old, and her siblings accepted her as the perfect little princess she was.

Fortunately, Hindy's older sister Toby was a born therapist. By the time Hindy was three years old, Toby was nine. She would build an enclosure out of Legos and put Hindy inside with some toys. Then she'd say, "Find me the doll" and Hindy would grope for the doll, or "Find me the duck," and she'd feel around for it. In this way, Hindy learned to differentiate among different textures. Toby also taught her songs and the motions that went along with them.

One of my initial fears about Hindy's blindness was whether she would be accepted. Would family and friends relate to her normally? Would she be taunted or encounter discrimination? Kids can be brutal. I learned that people responded to the situation by following my cue. If I was comfortable with Hindy, so were the people around her.

Although I loved her fiercely, being comfortable with her disability was challenging. When she first started walking at the age of two, she would bump into walls and hurt her face. Whenever that happened, the reality of her blindness hit us powerfully. It was then that my husband finally broke down. Throughout her struggles with surgery as a baby, the concept of blindness had been somewhat theoretical. Now we saw what it actually meant.

It soon became obvious that she needed a cane. A cane is like a pair of eyes for a blind person, helping him "see" his surroundings. But that didn't mean I was comfortable with the idea. Although people could tell that Hindy was blind because her eyes were small and unfocused, I still felt that a cane would be like a neon sign announcing her disability. Hindy started out using the cane at home. When it was time for her to go out with it, my sister drove us to a shopping mall in another neighborhood. There we walked around with Hindy so that I could get used to being seen with her in public.

On one of my trips to Eretz Yisrael, I went to an amazing exhibition called "Dialogue in the Dark" in Holon. The museum is completely dark; no light filters in, and visitors are introduced to the use of a long cane. It was the first time I'd ever experienced what it must be like for a blind person, and I realized that without the cane I would probably have stayed there forever, afraid to take a single step. I finally had a sense of Hindy's experience. Sighted people don't understand how many obstacles and pitfalls the world presents, from sidewalks to potholes to soft, shaggy grass.

Living without sight means that Hindy is missing out on a lot of the world's beauty and pleasures. We talk to her a lot to compensate for her blindness. The saying "A picture is worth a thousand words" is so true. Much of what we know about the world we learn through the faculty of sight. I was once looking at a toy car and was amazed by how many different textures, shapes and colors it had. The wheels had grooves and bumps; the color was gray and shiny, and the windows were transparent. I point these things out to Hindy continually; I can't take for granted that she'll somehow acquire this information through osmosis. I've taken to describing the littlest objects and the biggest experiences. I talk to Hindy much more than I talked to my other children when they were growing up. As we walk, I tell her which street we're on, which one we're passing and what's going on around us. When I help her with her clothing, I tell her which colors she's wearing. It's hard to explain color to a blind person, but Hindy remembers that milk is white, the sky is blue and grass is green.

I also make sure to use "regular" language that isn't stilted, because it's important for her to speak the language of the sighted world. For example, she'll say, "Let me see that" when she wants to feel something.

She also has to work harder socially. One of the things she absolutely hates is when people come over and want her to guess their identity, even though they're probably trying to make her feel smart. It's sometimes hard for her to identify the voice even if she knows the person well. It makes her very uncomfortable and nervous. When you talk to a visually impaired person, the correct thing to do is to identify yourself first. In school Hindy is sometimes at a disadvantage when her friends expect her to respond to a nonverbal cue. They have to address her by name so she knows that the conversation has turned in her direction.

Luckily, Hindy has been blessed with a great sense of humor. Many years ago, when I was still walking her to the bus stop, there were many mornings when it was still dark. One particular morning she commented on the darkness, and I expressed my amazement at her ability to perceive light. "What do you

think, I don't have eyes?" she said. Or sometimes she'll get annoyed when things are strewn around the floor. "Doesn't anybody know that there's a blind child in this house?"

She's incredibly talented and has written a song about her life story. It takes almost superhuman strength to be an average person with such a severe disability. Even something as simple as pouring a cup of orange juice involves finding a cup, holding it exactly under the flow and knowing when to stop so it doesn't overflow.

Up until three years ago, Hindy didn't realize how different she was. But once she did come to this understanding, she wanted to know what was wrong with her eyes. With the help of Uncle Moishy's song "We Are All Different," I explained to her that we all struggle in different areas. Our job is to treat everyone with respect and use the strengths Hashem has given us to do our best. I keep telling her that it's okay to feel sad, upset or frustrated sometimes, but it's not okay to stay that way. I listen to and validate her feelings, and she feels comfortable discussing her hardships with me. I'm often amazed at the things that come out of my own mouth. It's as if Hashem is talking directly through me, enabling me to help her.

When I asked Hindy if there was anything she would like to add to this article, she said immediately, "You just have to overcome your challenges." Then she added, "Don't judge anybody because of how they look. Find out who they really are before making a decision."

After starting off with Jawonio [a provider of services for people with special needs] in New City, we decided to send Hindy to the New York Institute of Special Education in the Bronx. We weren't comfortable sending her to a non-Jewish school, but our rav felt that it was crucial for her to have the life skills she would acquire there, such as how to navigate the world with a cane and how to read Braille. It was very difficult for her to integrate the two worlds of home and school. In fact, she never talked about school much. Fortunately, the first teacher she had there was a frum woman, which greatly eased her transition. A kosher pizza shop had also opened up in the Bronx, so we were able to order hot lunches for her.

When Hindy was ready to be mainstreamed, we enrolled her in Cheder Chabad of Monsey. She is now almost 12 years old, in a class of 20 six graders, with a shadow to help her function as independently as possible. I work in the school and am always nearby. The day she started there, I felt like saying Hallel. It was a day of intense joy. We had someone come in to talk to her classmates and explain what it's like to be blind. I am very grateful for her classmates' acceptance of her.

Not everyone, though, is as enlightened or as welcoming. When people stare at her, I'm sure she can feel it even if she can't see what's going on. It makes me feel very uncomfortable. Blindness is a relatively rare disability. You see more children who have Down syndrome or are confined to a wheelchair. It's also something that's frequently misunderstood.

Luckily, we have a few good resources. CSB-CARE (Computer Sciences for the Blind) is an organization founded by Rabbi Nachum Lehman that translates sefarim, siddurim and other Jewish texts into Braille. One of the many technologies he created is a computer program that enables blind people to navigate Tanach, Shas, Mishnayos, Shulchan Aruch, and hundreds of other works by audio or refreshable Braille display. He also publishes large-print sefarim for people with limited vision. He has truly been a life saver for us. Thanks to his organization, Hindy has all the sefarim she needs for school in Braille. (Hebrew Braille is based on the English alphabet—i.e., alef is A, beis is B—and is also read from left to right, but the nekudos are represented by different dot combinations.) On Rosh Hashanah, people couldn't stop marveling at how she was able to daven along with everyone else from her Braille machzor.

Unfortunately, there are more blind people and children in the world than I had imagined. Another woman and I started "Insight Beyond Eyesight," a conference call that features inspirational speakers. It's important to network so we can strengthen and help each other.

I'm always looking for things that Hindy will enjoy doing. She doesn't like games. They're hard for her to play, even though there are board games and dice in Braille. She enjoys schmoozing, but most girls her age treat her as if she's younger than she is, so she sometimes has difficulty finding conversation that works. We know of a girl in Boro Park who is also blind and reaching out to her for suggestions has helped a lot.

I used to read the Aim! magazine to Hindy every week, and she couldn't get enough of it. So I contacted Ami and asked to get the computerized version. I now spend a few hours a week converting the PDF file to text. Then I convert it to Braille and print it out so that she has her own copy of Aim! to read on Shabbos, just like any other girl.

When Hindy's blindness was confirmed, we were plunged into a world of darkness. But seeing our daughter flourish despite her disability has been a tremendous joy. With the help and support of family and friends, as well as all of the chesed organizations with which klal Yisrael is blessed, we were able to see Hashem's hand every step of the way. Not only do we have tremendous nachas from our daughter, but she is a source of chizzuk and inspiration to all who know her.

We found the light at the end of the tunnel.