



VISIONS OF GREATNESS

• Rochel Bodek •




“Insight beyond Eyesight”
☞ “When You Learn, Teach,
When You Get, Give” (Maya Angelou)

“Giving is a Gift to Oneself”
(Rabbi Yechiel Spero)

The above verses are my mottos, my ambition, my messages for life, although it took a long journey for me to come to appreciate their deep meaning, and, it's still a work in progress....

My father is legally blind due to **Atypical, inverse** Retinitis Pigmentosa (RP) and my mother has Post-Polio Syndrome and is wheelchair-bound. Nevertheless, our home was a fairly stable one and my childhood was uneventful. There were times where I felt somewhat self-conscious of my parents because of their disabilities, but for the most part, I was very proud of them and tried to help out as much as possible.

I started wearing eyeglasses at a very young

age. Up to the age of ten or so, with frequent prescription **as adjustment**  my vision was relatively correctible. I had enough sight to read a standard print and go about my daily living activities with nary a hitch. As I approached my teen years, my eyesight began to further deteriorate to an extent beyond correction with glasses. I was diagnosed with RP, the same eye condition as my father and siblings. At around age thirteen, I was officially classified as legally blind.

What does legally blind imply in laymen's terms? Perfect vision is 20/20. That means that one can see everything well and clearly from a twenty feet distance. To be considered legally blind one has to have 20/200 vision, which means

that what you would see from twenty feet away, i.e. the big E, that person would see it as if it would be from a distance of two hundred feet. That is a huge difference. (This categorization varies from country to country, I am not sure why. There are some countries where the criteria is 20/350, so a person has to have much weaker vision in order to be classified as legally blind and to be eligible for services, compensation and accommodations. There are some people who are totally blind and have no light perception at all, and some who have mild light perception

I struggled through my adolescence with emotional crises of regular tenor compounded by my visual impairment. It was extremely difficult for me to accept that I would never see 'perfectly' again, be stigmatized as 'disabled', and have to be dependent on others in so many ways. I felt hopeless and despondent. These issues (which I can only identify years later in '20/20 hindsight') define some characteristics of my personality: yearning for perfection and desire for independence. I couldn't see how I could have a future with a lack in these abilities.

It took a lot of strength and courage, support from family and friends, as well as professional intervention, for me to come to terms with my vision loss. I began to change my outlook on what a meaningful life is all about. Once I determined that I could strive for aspirations despite my vision impairment, I started exploring options of building my future, of persevering. I eventually learned how to use a special magnifying screen known as the CCTV, which enlarges any text placed underneath a lens and the size and color can be adjusted. I taught myself how to write with this equipment as well. I subsequently got a CCTV at school, which facilitated my academic progress. I also learned how to read and write Braille with the kind coaching and guidance of my Teacher of the Visually Impaired (TVI) provided by the local school district. Furthermore, my TVI ordered some of my English textbooks in audio version on cassettes and some of my books in Braille. I studied hard in high school and excelled academically.

The year after I graduated I got married. Mazel Tov!

My husband is a paraplegic due to a neuroblastoma that occurred during his youth. He uses a wheelchair to get around, yet he's a very capable, bright, and independent person. We both share the philosophy of being as independent and productive as possible despite our disabilities. We are proponents of focusing on abilities and trying to make the best of what life throws at us. This is easier said than done of course, but being where I am today certainly proves that we invest tremendous effort to live by this principle.

Beh, my husband and I were blessed with adorable twin boys who are now eight years old. Although there were some challenges along the way as parents with limitations, we try to raise our kids and provide them with the best cluck we can. Our children are aware of our disabilities and its ramifications, as we are very open with them about it. Even though we do some things differently than other parents, we invest our utmost efforts to provide our children with a relatively normal upbringing.

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So, at this point how does my daily routine differ from yours? How do I go about the usual stuff with limited vision? Really my day is probably more similar to yours than you think. I too have to be there for my husband and children, make sure the laundry is tackled, do homework with the kids, get to work on time, cook, socialize a little, shop, run errands, pay bills, keep dentist appointments, and still find time to enjoy the gift of my family and my health. Sounds familiar? Ok. Ok. So I do have to make some accommodations here and there, but by and large the pattern of our days probably follow the same trail.

How do I know what to wear in the morning? How do I know which skirt matches which top? Which jacket belongs to which twin? When the eggs are boiling? What time it is? Most solutions are practical and simple, and like everything else, take getting used to.

I received Rehabilitation services through the Association for the Visually Impaired (AVI), a local

agency servicing the visually impaired. My rehab teacher provided me with various items and tips to help me run my household more independently and efficiently. For instance, she gave me a Braille labeler and tactile dot stickers to mark appliances and devices so that I could operate them on my own. We put dots next to each oven and gas dial by the three, six, nine points, so I could know how



high the flame was. Additionally, she presented me with individualized measuring cups and spoons; an individual $\frac{1}{4}$ cup, a $\frac{1}{2}$ cup 1 cup, so by size and adding the amounts I can get to the exact measurements when preparing food.

We then came up with a solution for measuring the formula and water when making bottles for my twins. My teacher cut special grooves in the bottles by the right measurement mark so I could feel the spot.

Some people have the mistaken notion that people who are able “read” Braille by feeling the dots, can also feel raised numbers and letters, like on a bottle or credit card. But, it’s really very different and I can’t know which card I want to use based on that. So how do I choose the insurance or credit card I need? I try to be very organized. Looking for things is very time-consuming and frustrating so I create a system in my pocketbook, in my wall, my drawers. For example, I keep twenties and fifties in different compartments in my wallet. I keep different credit cards in different pockets, so that I am confident I am using the right one without double-checking or asking for assistance.

The same goes for the fridge and kitchen cabinets. I am very meticulous about putting specific things in their designated places so I don’t have to fumble to find what I need. I try to teach my husband and my children to follow the same system in placing things

exactly where they belong, and they are pretty good at it.

Regarding my and my children’s clothing, I concentrate on buying things with easily recognizable tactual differences like zippers, buttons, snaps, cottons, wools, outside pockets, etc. I try to make some differentiation between my twin boy’s clothing too. For example their jackets

are different sizes, so I put a button on one tag. the tag fell off, so that became my “*siman*” for which one belongs to whom. For color and style I always go shopping with someone. Whether it’s my husband, one of my sisters, or a friend, they know me and what I am comfortable with. As far as cleanliness goes, it’s usually my husband who double-checks so it’s, “Ask Totty.”

My kids are not the only “things” that have to be kept clean. My kitchen, and the rest of my home fall into the same category. I’ve found creative, innovative, ways to do that and with the help of my husband and children, we manage well. When I sweep the floor, I follow the same thorough pattern every time, a system that ensures I don’t miss any spaces. I also get down on my hands and knees, (yes!), and feel with my hands if I did a good job. I wash my counters and again go over them with my hand feel if any tiny crumb or dirt escaped my vigorous sponge-down.

I tell time by using a talking watch. It was one of the gadgets my teacher offered me, but it took a while for me to start using it, since I was self-conscious about making it talk in public. Eventually I got used to it and have a talking watch at all times to this day.

Going to the supermarket is another challenge. I pull my cart behind me rather than push it ahead of me I generously “spare” some people’s toes and ankles. Occasionally use my portable CCTV to “read”

cereal boxes, detergents and the like and my kids enjoy helping me. I learned to ask for help when I need it, especially when choosing loose vegetables.

By sight, for example, I ask what's on my plate and if there is a salad bar or Viennese table, I will ask someone to tell me what's available and to serve me. I rather not touch the food and/or mess things up. In that way I can have my cake and eat it too!

I smell things before others around me do, and often I hear things other people don't pick up. I don't think my senses are stronger, I think I compensate for my vision by being more attuned to my surroundings. I've been asked if the fact that I had good vision during my youth makes life easier and the answer is definitely yes. If things are described to me, like specific shape, color, size, etc., it's very helpful in getting me to visualize what I can't see. As far as my kids are concerned, I recognize them by their voices and, believe it or not, their footsteps! I cannot really see their faces and pictures do not get enlarged clearly on my CCTV, but generally I am not so desperate to see well as I am to connect well by communicating well.

How do I get around on a daily basis, to work to appointments, to the supermarket mentioned above? My Orientation and Mobility (O&M) instructor worked with me to improve my independent travel skills. As part of my training, my O&M instructor introduced me to the cane, taught me how to use it properly, and purchased one for me. However, my peripheral vision is fairly good and I can generally see enough to get around without using a cane. Yet my O&M instructor emphasized that a secondary goal in using the cane is for others to identify me as an individual with a visual impairment. But I was rather hesitant about utilizing the cane primarily for this reason, since I had no interest in



'advertising to the world' that I had limited sight. So, for the time being, my cane remained in my speech demonstration bag. I know this might sound silly, but somehow every time I would think of using my cane an old jingle would come to mind. Remember how we used to sing, "In came the teacher with a big fat stick..."?

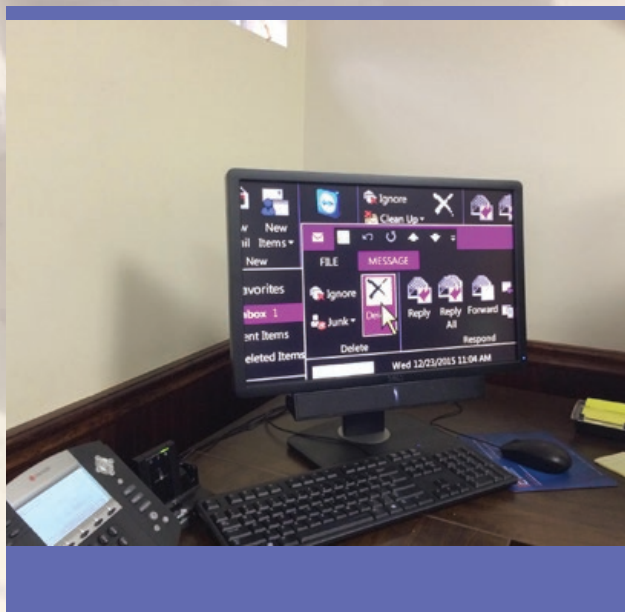
Shortly after I completed my O&M training, I started speaking in schools and at public gatherings about my disability. I discuss how I live and function as independently as possible in spite of my vision loss. As part of my lectures, I show Braille and devices visually impaired individuals use. And, of course, one of them is the cane. I would explain its purpose and state that I didn't really need to use it, as my vision loss is not severe. Sometimes, I would even jokingly state that my O&M instructor thinks it would be good for me to use it just for others to identify me as an individual with a visual impairment and then proclaim: "That's exactly why I don't want to use it".

At this point, I went for some training in another area, using more assistive technology. I have an accessible phone loaded with software to assist the visually impaired. There's audio software that reads text to me, and software that reads back to me everything I do or write. I know I am sending the correct message or email to the appropriate person or looking in the right place for the information I need. I can take a picture

of any text, information on a product I want to buy, and it will read the information to me. There's a digital talking book file where I can download mp3 text files and then listen to them. I also own a portable CCTV, which I use with a pen, it is magnified on the screen that I can see what I am writing, and then it comes up in type.

The wonders and marvels of modern technology!

I learned how to use and obtained special software on my computer called Zoomtext, which enlarges the text and has a screen-reader, which reads the text out loud to me as well. The combination of large type and audio feedback facilitates my computer navigation skills. AVI's vocational specialist helped me create a resume and tried helping me find a job. She emphasized that there



was no need for me to write on my resume that I was legally blind as, according to the federal Americans with Disability (ADA) Act; an employer must hire me if I felt I could execute the job requirements with reasonable accommodations.

I had seen an ad in the local paper for a position as a Service Coordinator. I thought I met the requirements to fill this position and submitted my resume. That agency contacted me and they were pleased with my resume. However, when I mentioned that I was legally blind, they chose not to give me the job. I noticed another ad for the same position at a different agency and decided to try to apply there as well. This time, I elected not to tell them anything by phone and figured it might make a better impression if I presented myself as a capable person at an interview and then mention my disability. This strategy worked well and I was ultimately hired there. About a year ago, I had the privilege of being offered a Service Coordinator position at Rayim. I accepted this offer and am a proud member of the Rayim family.

Working at Rayim is a wonderful experience. They have accommodated all my needs in an amazing way. My computer, and the programs and devices I need to be productive and efficient, were all provided happily and willingly. However, more importantly, the atmosphere is pleasant and conducive to accomplishing and working successfully. When I heard that there

was a Bluetooth available that would connect to both my phone and my computer (for the audio), it was procured for me and has made a huge difference in the ease and speed I can use both. I keep my desk neat and organized, a prerequisite to my being resourceful and competent, and I file things in the order they happen before I go on to anything new.

I work with passion, because my heart is in it. I understand first hand what it's like to need services and how confusing and difficult it can be to navigate the system and to be aware of the available services. I want to help as many people as much and as quickly as possible, and at Rayim I am enabled to do just that!

Several years ago, AVI hosted a Vision Awareness Seminar and I offered to give my **typical** lecture at their event. After my talk, an O&M instructor for the NYS Commission for the Blind, **came over to me and stated:** "If you are trying to make your community aware and sensitive to individuals with visual impairments, don't you think you should be a role model and use your cane even if you don't need it as much for your own visual need?" An argument ensued amongst a few of the participants. My O&M came to my defense and said that I need to feel comfortable using the cane and everyone needs to do it at their own pace....

I came home and thought a lot about **th** but couldn't get myself to entertain the idea of using a cane. The stigma attached to it was too much for me to bear. As aforementioned, my father has the same eye condition as mine. He only started using a cane very recently when he absolutely needed **;** he was bumping into things and tripping on objects. And even then, it was quite a challenge for him in the beginning. This further discouraged me from using the cane.

Yet with time, I started realizing that the

cane can be helpful for identification purposes sometimes. Therefore, I did try using the cane on some occasions. My husband had a major surgery about two years ago and I figured if I had my cane with me at the hospital it might be easier than having to explain to everyone that I was visually impaired. I mentioned this to my mother in law who was present at the time. Surprisingly, she wasn't as shocked as I thought she'd be and agreed that it might be a good idea. I had the cane parked next to me throughout the duration of the surgery and afterwards, when we received the great news that all went well, I nearly forgot my cane in the waiting room and my mother in law remembered it at the last second!

I attended AVI's first White Cane Awareness Day in Rockland County about a year and a half ago. My dear friend, who's totally blind, and her entire class were present. I went over to her afterwards and told her I was making a resolution to start using my cane more so that she will feel more comfortable using hers. My cane moved from my speech demonstration bag to my active pocket at that point. (The cane is foldable and fits in easily.) But though I did use it here and there, I was still uneasy about just walking out with it in the community. I used my cane once in a while with some negative and positive outcomes.

For instance, I once used it when I walked into a local bank. I figured instead of having to explain why I needed help completing a form, they'd just see me with my cane and understand. Believe it or not, when I walked up to the teller with my cane in tow and asked for help, she asked: "Why do you need help?" I answered because I was visually impaired in a not too pleased manner. On another occasion, I needed to do fingerprints for a new job located in a local hotel. When I walked in with my cane, the woman behind the counter immediately asked where I needed to go. She offered to show me where it was right away and even asked: "Can you see enough to follow me? do you want to hold onto my arm?" There are all kinds of people out there, and most of them are kind.

"God has given each one of us a task, which we can perform better than anyone else. We must find out what that task is, and how to do it in the best way possible"... "What really counts in life is the quiet meeting of a very difficulty with the determination to get out of it all the good there is" (Helen Keller)

At this point in my life, I thought I had met my share of challenges and felt content and proud that I had overcome them with flying colors. But in a matter of time, Hashem chose to test us once again. The most difficult test of all was yet to strike. The older of my twins has been diagnosed with RP and is already legally blind. Observing him struggle is a cause of daily pain and heartache. It seems like an insurmountable hurdle. But I keep telling myself to move on and try to make the best out of this situation.

There is a very special heimishe organization called Computer Science for the Blind, CSB Care. They provide technology and software to assist the visually impaired and disabled. The amazing thing about this organization is that they customize the enlargements or the Braille based on your individual specifications. It is largely to their credit that my son can use a siddur, a tehillim, and a chumash. They prepare things for him in Yiddish, like his chumash translation and print children's stories and books that can be used Shabbos when computers are muktzah. The opportunities, both in learning and enjoyment they have made possible for us are tremendous!

So although there are fortunately people and devices to simplify our challenges, I found myself yet again having to figure out novel strategies to deal with our new circumstances, in a proactive way. While advocating for my son and researching appropriate resources and services, I've encountered many obstacles and am constantly learning new things in this field.

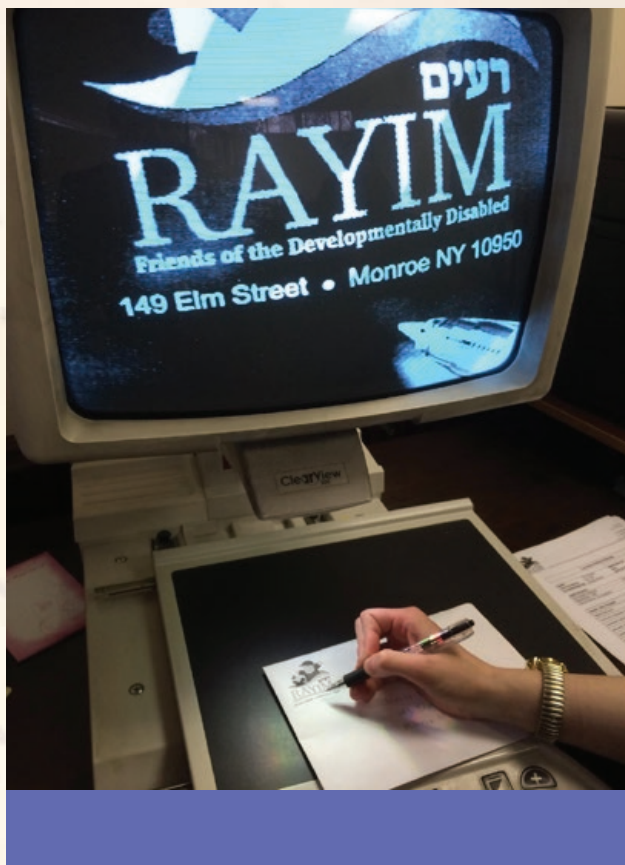
In the interim, I've started networking with other parents and professionals with visual impairments and have been involved in bolstering the support system for parents of the visually impaired. Another mother and I have coordinated a frum support group for mothers of visually impaired children called 'Insight Beyond

Eyesight'. This has become my focus and mission. I am now pursuing a degree in Education Certification and hopefully eventually becoming a Teacher of the Visually Impaired.

This past summer, my son attended the National Federation for the Blind's Braille Enrichment and Literacy Program. The primary focus at the program is encouraging the kids to use canes and to improve their Braille skills. We borrowed a cane for my son for the program and they actually gave him one of his own as well. Afterwards, another

mother at the program mentioned to me that she had asked my son whether I used my cane and he said "Not really". This was a wake up call for me and made me recalibrate. I said to myself "if I'm not comfortable using the cane, how can I expect my son to use it?" This gave me the final push to start using it more 'out in the open'. I prepped my husband and kids on this and declared that Hashem gave me the visual impairment and I didn't choose it. Thus, there is no reason for me to be embarrassed about showing everyone that I am visually impaired. I officially now use it when I walk to work and am gradually using it more and more.

I recently asked my son whether we should use the cane while walking somewhere, he instantly responded "Of course, then all the cars will stop for us". That gave me a laugh and a boost. He's not so wrong about it either. Vehicles are definitely more aware, considerate, and patient when I walk past them or cross the street which makes me much safer as a pedestrian. Besides Hashem. And truthfully, the cane is also beneficial for my visual



needs, especially when it's dark, when there are stairs or obstacles I might not notice, etc. I've had more positive experiences than negative since I've been strolling around with my cane. Last week, while walking on the street, a man cautioned me to be careful about a piece of plastic on the ground. I was caught by surprise and just walked on without responding. I then thought to myself: "I should've told him hello, that's what the cane is here for" but then I thought: "He was just trying to be helpful and I should've said thank you"

I don't know if and when I will be completely comfortable using my cane but I'm using it regardless and am actually benefitting from it and hopefully so is my family and community and the greater population at large. I have adopted a new mantra and keep saying it to myself and others "if you want to do or use something that will help you, as long as it's not hurting others, there's no reason for you not to do or use it".

I have read many biographies of individuals who are visually impaired, and others who have prevailed over hardships and obstacles. Some of them have mastered outstanding feats and reached great heights. I would love to emulate some of them and make the world a better place. But I've come to the realization that the best I can do is contribute my share, to my utmost potential, on a small scale. My hope is to acquire the capacity and knowledge to teach and advocate for children so that they can recognize their capabilities and achieve their dreams. As Helen Keller so eloquently remarks "it is not required of every man and woman to do or be something great. Most of us have to be content to take small parts in the drama of life"