נשמהלה Neshamale magazine

Sharing Our Special Experiences: Chizuk & Inspiration

EXPLORING: THE BAR MITZVA

A SPECIAL SIMCHA FOR A SPECIAL BOY /21

LET'S GET EDUCATED: VISION THERAPY /28

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In the incoming Rosh Hashana issue we plan to print a section on the topic of "**The potential within: How do we measure it? How do we actualize it?**". We are looking for your input to help cover this theme from all angles. Please submit your articles, stories, poems, thoughts, concerns and advice that may be of interest. Your anonymity will be protected if requested.

We always welcome, Wow! Stories and Sweet Spices (hashgacha) stories, as well as any questions you may have for a Rav, a doctor, or a social worker.

Deadline for submissions: **August 10**
Email: **neshamalemagazine@gmail.com**
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Dear Readers,

It was a chilly winter night when I drove across town to wish Mazel Tov to the Dickstein Family, on the occasion of Yehuda's Bar Mitzvah. Since his wonderful mother is the best co-editor I could wish for, (planning it out, writing so many of our favorite columns, and keeping me going with her encouragement and creative ideas), I wanted to take the opportunity to join in their *simcha.* As I turned the corner onto their street, the most amazing sight met my eyes: bumper to bumper traffic—on a quiet side street, on a quiet evening! The sight of so many cars filled with people searching for parking spaces made it look as if a major event was going on. And indeed, it was.

Yehuda, whom many of us have "met" through these pages, was celebrating his Bar Mitzvah, and no one wanted to miss it. As I joined the throngs of people walking towards the Dickstein home, I knew at once that we would focus on Bar Mitzvahs in an upcoming issue. I was intrigued by it all: How do the parents of special boys plan such an event? Do their boys enjoy being the center of attention? What are the parents' thoughts and emotions on this momentous occasion? How do they ensure that it will be a happy celebration?

The answers I received did not disappoint me. Although I am not anywhere near the stage of thinking about our Avrumi's Bar Mitzvah, I really enjoyed putting together this issue and gained a lot in the process.

One aspect I appreciated was the unique way that each boy's day was celebrated. I spoke to many families as I researched the topic, to find out their concerns and how they handled the practical aspects of the event. I heard everything from: "We didn't do anything – anything out of his routine would simply overwhelm him," to: "We went all out; after all, this will be the main *simcha* in his life." I heard about intimate family gatherings, and events where the whole town showed up. I read about boys putting on their *tefillin* in a facility, in the quiet of their own living room, and at the *Kosel* amidst a huge crowd. The variations were endless—which just goes to show how each of our *neshamales* are so unique and individual.

I sometimes feel that "outsiders" plunk all our children under one umbrella of "special needs" and assume that they are all more or less the same. (It reminds me of when, in my school years, a friend and I used to visit an elderly lady on Shabbos afternoons. The first time we showed up, she asked us if we were twins. We looked at each other in astonishment—we looked completely different from one another! But we realized that, to this woman, two "*Bais Yaakov* type" girls, both modestly dressed, wearing their hair in ponytails, looked identical!)

But we, who are part of this wonderful "nation" of special needs children, know quite well how their personalities, abilities, and challenges are all so different from one another. Even children with the same diagnoses are by no means "the same"—each is truly a world onto themselves.

It was also beautiful to see how every family tailored their Bar Mitzvah celebration to match so perfectly with their child's temperament, with what he would truly appreciate, and with what would bring out the best in everyone involved. The fact that each family was able to accomplish this (while leaving their egos and their dreams of a "typical" Bar Mitzvah behind), is a wonderful indication of their genuine acceptance of who their child really is.

Every family I spoke with (many of whom you will read about in this issue) conveyed immense pride and appreciation for the special child in their family. But even more than the acceptance, even more than the pride, was something else: respect. I realized that, in order to prepare an appropriate *simcha* for their child, there had to be a sense of respect for who the child is in the first place—respect for his soul, for his challenges, for his strengths, and for his role in this world.

Other than planning *simchas*, we can apply this attitude to many other situations regarding our children. Sometimes I wonder how differently I would treat Avrumi if he could only talk and let me know what he wants. But the truth is, when I sincerely have his best interests in mind, then, with Hashem's help, I can usually figure out what would be best for him.

We are constantly making decisions for our special needs children. Whether it's making summer plans, deciding on a bedtime, or something as simple as what to serve them for supper, we can try to be respectful by taking their personalities and partialities into account. When children cannot express themselves clearly, who more than their very own parents, who know them the best, should be there to relate to them with both love and respect?

I would like to end off by sharing with you something that really wowed me. I asked a mother if we could use her son's name and photo in the article about his Bar Mitzvah, or if she wanted him to be anonymous. Her response? "I'll have to ask my son if he is ok with that. I'll get back to you."

Isn't that just a perfect example of having respect for our special children? After all the (sometimes "fluffy" ideas of) loving and accepting our special children, here is a mother who sees her son as a real person; who relates to him with genuine acceptance, pride, appreciation, and respect.

I hope to be like her one day.

Chayala

INBOX

Dear Fellow Readers,

I want to comment on the *Smart & Safe* column in issue #10 regarding tips for mealtime. One item mentioned was the Rifton Activity Chair, which comes with a tray to use for mealtimes. The author wrote that since her insurance covered only 50% of it, she did not feel it was worthwhile.

My insurance did cover it, B"H, and I want to say that I have found it to be very worthwhile. Initially, I was wary about getting it, as it is very large and takes up a lot of space. I also didn't think that my son would be happy being buckled into it. However, we ended up ordering it, and are really reaping the benefits. It is very comfortable and the tray is huge, which is a big plus in keeping food off the floor. It is great for mealtimes, activities, and arts and crafts.

It is also a comfortable place where we can "contain" our son if his behavior is out-of-bounds. In the past, when he needed to be contained, would put him in a closed room, which he really resented. Now, I simply buckle him into his chair and he can stay with us in the same room.

While it does take up a lot of space, it is a lifesaver when it comes to calmer Shabbos meals and the like!

Hatzlacha! A Reader

Hi, I am responding to the Letter to the Editor in Vol #10 about insurance coverage for diapers. In my experience, not all diapers are created equal. Make sure to find out from your insurance all the options as to which companies you can order from. If you are not happy with one company, it's easy to switch and try a different one. Since many of these diapers are not the greatest quality, you may need to double them at night.

Naomi M.

SUPPORT GROUPS

The usual challenges of parenting are compounded for parents and primary caregivers of children with special needs. Among the many challenges they face are learning the nature of the child's disability, researching and accessing effective treatment and resources for the child, advocating for appropriate school placements, and getting to innumerable appointments with doctors, therapists, and school personnel.

Perhaps the most difficult part of it all is learning to cope with the emotional demands of caring for an individual with a disability. The emotional impact can be enormous, and may include a multitude of feelings such as worry, guilt, and isolation. Parents worry about their child's future; they fear that they are not doing enough, or not doing the right thing for the child. Parents experience guilt over their limited ability to help their child, and the loss of attention toward their other children. They are liable to blame themselves for being envious towards those with "normal" children. Feelings of isolation are often experienced because, due to the child's disability, you miss out on many family-oriented activities, and you may encounter criticism from others who do not understand your child. The burden of stress is great for these parents—a recent study found that mothers of adolescents with autism had stress hormone levels comparable to soldiers in combat!

According to research studies, mothers of children with special needs are often exhausted and frequently experience resentment. Their reserves of time and resources for self-care are even more depleted than those of parents of typical children. yet their need for refueling is greater. To be sustained through the marathon of caring for a child with special needs, it is essential that parents attend to their own needs. As the saying goes, we must remember to "care for the caregiver."

Getting the support you need is critical, and can be done in a variety of ways. One way is by joining a support group. There are many potential benefits from participation in support groups. Participants listening to the stories of others realize they are not alone. A support group is a safe and supportive environment in which to share feelings and life circumstances. New skills like stress management can be learned and practiced within the group, and as you learn more effective ways to cope and handle difficult situations, you gain a better understanding about yourself and your needs.

In recognition of all the above, two new support groups are being formed. One will be in-person and take place in Lakewood, NJ; the other will be via telephone. The groups are facilitated by Brani Rosenblatt, MMHC, who has worked in the field of trauma and addiction, and is the mother of a special child herself. The groups will focus on the mothers, rather than the children, and help them through their challenges. The goal is to provide camaraderie and a safe place in which to share your struggles. We will discuss effective DBT (Dialectical Behavior Theory) skills which promote emotional regulation and enhance self-esteem. The support group can also help you to gain increased insight about the factors that have contributed to your current challenges, and discuss strategies that seem to work best, to help you in the future.

Groups will meet weekly and run for six consecutive weeks. For more information please contact Brani on her confidential voicemail at: 732-364-7914, or her confidential email at: njcenterforgroupwork@gmail.com.

Chizuk Boost #4

Adapted from a talk by Rabbi Boruch Rabinowitz

There's an amazing insight from the *Magid* of Mezritch. He says that שבע יפול צדיק וקם ("A righteous person may fall seven times, but gets up." –*Mishlei*/Proverbs, 24:16) means that the entire purpose of the "falling," the entire purpose of whatever challenge or struggle we have, is to bring out the latent power, the sparks of glory hiding within us. Each of us is blessed with unlimited potential, and as the Ramban explains, the purpose of being tested is to actualize this hidden potential.

For the most part, the only time that a person is really going to dig deep within himself, to find *kochos* he doesn't even know exist, is when he's under pressure, or when life is difficult. How does a piece of coal become a diamond? When it's under pressure!

Years ago, when my son was in the hospital, I would stay all night with him, then drive from Great Neck to Staten Island, where I was teaching—a long, gridlocked commute. On basically no sleep, I taught the entire morning, went home, showered, and laid down for a few hours of sleep before my wife returned from her "shift" at the hospital, and I would go back again. One day, I had barely laid down when the hospital called, saying it was urgent that I come immediately. Functioning on only a half hour of sleep, I got in the car, drove out to Long Island, and did the entire night shift again.

I could only do this because *Hakadosh Boruch Hu* put unbelievable energy and potential into us. There are times when we need to call upon those powers that Hashem grants us, and sometimes the only thing that's going to bring out those powers is challenge, is difficulty. Our challenges help us actualize our very existence. By facing adversity, we become better, more complete people. If not for challenges, these qualities would never be accessed; they would simply lie dormant.

The *Magid* tells us that real *simcha* is achieved when a person works to reach his own *shlaymus*, his own sense of fulfillment. When we start a project and map it out and accomplish it, we have tremendous joy. When something comes too easily, the joy is short-lived. Real *simcha* comes through finding new energies, new talents within oneself, and utilizing them to meet our challenges. These challenges ultimately connect us with *HaKadosh Boruch Hu* to a greater degree. Seeking out *refuos* and *yeshuos*, living a life of joy despite our difficulties—that brings *simcha*.

Based on these ideas, I am going to suggest the following *p'shat* on שבע יפול צדיק וקם. Generally speaking, a person thinks: "When I do *Ratzon Hashem*, I'm accomplishing, I'm doing *mitzvos* and learning *Torah* and everything else – I'm good. And when I'm doing things that are not so great or I'm failing, I'm moving away from the *Ribono shel Olam*." What the *posuk* is teaching me is that even when I don't succeed 100% (and who does?), my failure itself can bring me closer to Hashem.

The *nefila* (falling) is what gives me the chance of *kima*, of rising again. And it's all by the design of the *Borei Olam,* Who planned it this way. Life is a series of ups and downs—that's what makes it exciting and challenging; that's what makes life enjoyable. When I'm up, I'm up. And when I'm down, I need to take the *kochos*, the knowledge, the awareness, the connection I made to the *Aibeshter* when I was up, and apply it so that I can bring myself back up again.

The message of שבע יפול צדיק וקם is that it's all designed by Hashem. I can't expect to stay at one plateau the entire time—I need to accomplish, I need to grow. With more growth comes more fulfillment, more accomplishment, more interaction with other people. The higher we climb, the greater our degree of *simcha*.

שבע יפול צדיק וקם – the *rasha* gives up after one time, he throws in the towel. But the *tzadik* is "sheva," which means 7, 8, 9, 10, 100 times, he can be faced with challenges, and he's going to embrace the challenge as a way to grow, to connect with Hashem, to find fulfillment.

Yes, this world is challenging—maybe I look around at other people and say: "Oh, I wish I had an easy life like them…" Truthfully, everyone's got their *peckel*. Everyone has their unique way to grow the way *HaKadosh Boruch Hu* designed it. And every one of us has that ability of שבע יפול צדיק וקם, to be the *tzaddik*, to recognize our life's circumstances as part of Hashem's perfection, and "*v'kam*" – to rise up and keep climbing.

This Chizuk Boost is excerpted and adapted from one of Rabbi Baruch Rabinowitz's weekly 10 minute Chizuk shiurim for parents of children with special needs. There are now over 130 recordings, which can be accessed on Kol HaLashon (718-906-6400, press 1, 4, 97, 2).

Yehuda's Bar Mitzvah

Fraydel Dickstein

Pischu Li pe'sach shel machat, v'Ani eftach lechem pe'sach shel ulam. ("Open for Me an opening the size of the eye of a needle, and I will open for you an opening the size of a hall." *Midrash,* Shir HaShirim, 5:2)

I tried my best—and Hashem most certainly came through! Yehuda's Bar Mitzvah was truly a dream come true. In order to appreciate just how miraculous and monumental the *simcha* was, let me share with you some of the planning, the decisions, and the *hashgacha* that we experienced in the months leading up to his special day.

Planning Yehuda's Bar Mitzvah

I knew Yehuda's Bar Mitzvah had to be special, had to be monumental. I was taking this precious boy and hanging him as the "chandelier" in our personal *simcha* hall. He needed to look glamorous, the hall needed to look glamorous. We were proclaiming to the world that the *heilige neshama* the *Ribono Shel Olam* gave us is magnificent, he is our pride and joy, and we are so privileged to have him. We are filled with thanks to the *Ribono Shel Olam* for allowing us to be the epicenter of so much *chessed*. For allowing us to house this *chefetz shel kedusha*, this fountain of holiness, this *chelek Eloka mi'mal* who is not encumbered with a body and speech that blocks his connection to Hashem. He is pure, he is connected.

Our goal was many-fold. We viewed this Bar Mitzvah as a *seudas hoda'ah*, a time to thank Hashem for this wonderful *d'var mitzvah* that we are privileged to have as our very own dear son. My husband and my other son planned to make a *siyum,* so it would be a *seudas mitzvah* too. We also wanted to use the occasion to show the world our Yehuda, to put him on the map. He does not go to many family *simchos,* and I felt this was a great opportunity for the extended family to get to know him. I hoped it would help take away all the fog in everyone's perceptions about our special son. Since Yehuda will most likely need to be cared for *ad biyas goyal,* I felt the need to present him in a positive and beautiful way.

In terms of Yehuda himself, I kept my expectations very low. I was ok with him hanging out in the study playing videos the whole time. I even predicted that he would lock the door to make sure no one disturbed him, as he would be overwhelmed from all the people and noise. Of course, I tried hard to get the best staff to watch him, simply to ensure that he wouldn't run away if the door wasn't locked, or that he wouldn't engage in his favorite pastime and take a bath during the Bar Mitzvah.

Yehuda's Tefillin

The first thing we did to prepare for Yehuda's Bar Mitzvah, as probably is done with most boys, was to order his *tefillin*. I must elaborate on this miraculous occurrence. My precious, non-verbal Yehuda toilet trained just last year, at 12 years old. This is something I had 100% despaired of happening. When his teacher told me that she wanted to train him and believed it could happen, I said "I am not interested," and went on to extol all the virtues of diapers (I could have been a commercial for Prevail or Depends). Well, miracles happen, and this is something I can never stop thanking Hashem for, and never take for granted—Yehuda is trained! One Sunday morning my husband walked into the room and said: "I just hung up the phone with the *Rav*, and Yehuda can wear *tefillin*!" We were exhilarated! By that evening my husband had made a down payment on a pair of *tefillin*. The ball started rolling. Yehuda needed the most exquisite *tefillin* bag. I settled on leather, as I am not sure how fur reacts to *cholent* and *kugel* stains. We chose a stunning black and teal design, which just felt so perfect for my Yehuda.

Yehuda's Hat

Next on the list was a hat. At that point, we had not yet chosen a Bar Mitzvah date or hired a party planner, but I thought a special family trip to the store to buy a hat would help me figure out which direction to go with this Bar Mitzvah. I picked him up from his Sunday program and I said "Yehuda, do you wanna buy a hat?"

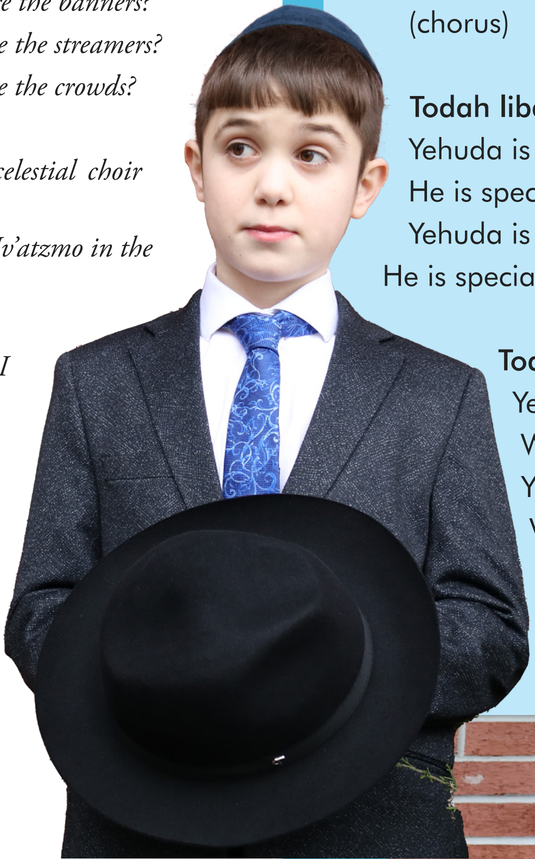
He shook his head yes vigorously, but I still was not sure if it was accurate. When I got close to the house, I called my husband and asked him to please bring everyone into the car and we would all go to the store together. I called the store to ask if it was a quiet time, and to give them a little heads-up about their next customer. When I got home, it took a full ten minutes to get everyone into the car. Miraculously, Yehuda just sat there waiting. (Yehuda is always out of the car door or window before I put the car into park!) The whole family walked into the hat store. Another miracle was that the store was empty – during Sunday afternoon prime time! Obviously Hashem was making the arrangements here.

We showed Yehuda himself in the mirror, and he could not get enough of himself in the hat. He was just beaming, and we were all ecstatic! At this point, I understood that my autistic child knows a lot more than we realize. He is proud and wants to be big, and Hashem would bring us exactly where we need to be. I came home on such a high.

Here is what I wrote that night:

YEHUDA GOT A HAT!
YEHUDA GOT A HAT!!
YEHUDA GOT A HAT!!!
YEHUDA GOT A HAT!!!!
YEHUDA GOT A HAT!!!!!
Where were the bugles?
Where was the band?
Where was the parade?
Where were the banners?
Where were the runners?
Where were the streamers?
Where was the red carpet?
Where were the crowds?

Ahh, if you listened closely- you saw a celestial choir along with a band....
You felt Hakadosh Boruch Hu B'chvodo Uv'atzmo in the room.
He said to His heavenly court:
"Look at My people who celebrate the life I have chosen for them!"
They don't question my ways!
They accept, they love and they thrive!
They feel truly blessed, and they are truly blessed!
They bask in my kindness and glory and
they feel peace and happiness!
They are blessed! Yes, we are so blessed!



This song was inspired by Nesanel Bamberger. Yehuda's brother sang it in SCHI's recording studio and the slide show of Yehuda was put to this song.

(Tune: **"Thank You Hashem"** by Joey Newcomb)

Chorus:
Ay di dy dy dy
Thank you Hashem!
Ay di dy dy dy
Thank you Hashem!
Ad di dy dy dy .....
Thank you Hashem for Yehuda!
Low part (two times)

Hodu L'Hashem Ki Tov!
Yehuda always has a smile on his face
that's the thing that won't erase
Yehuda always claps
Yehuda taught us many hacks

High part: (two times)
Hapa'am Odeh Es Hashem!
Yehuda, you're the best big brother
always bringing **nachas** to your father and mother
Yehuda Dickstein always cares for another

(chorus)

Todah libar ocho osher dibara
Yehuda is filled with love
He is special to the One above
Yehuda is filled with love
He is special to the One above

Todah Hashem! Thank you Hashem!
Yehuda's **midos** are so fine
With you we love to spend time
Yehuda's **midos** are so fine
With you we love to spend time

(chorus)

Hapa'am Odeh Es Hashem

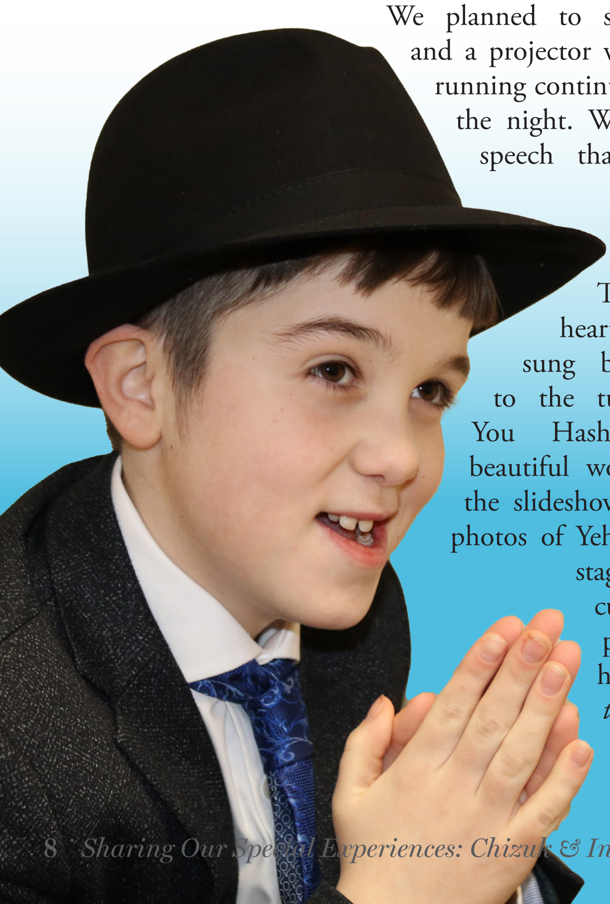
We continued to do our part in planning the event, all the while unsure if we weren't absolutely crazy and setting ourselves up for complete failure. We hired a party planner and tried to explain to her exactly what we wanted the tone and feel of the Bar Mitzvah to be.

As the date of Yehuda's Bar Mitzvah loomed closer, I *davened* to Hashem during *hadlakas neros* to help me wrap my head around this Bar Mitzvah so I could make it a reality. That Shabbos we read in the *parsha* that Leah named her son Yehudah, which means "He (G-d) will be thanked." My husband mentioned the *posuk "Hapa'am Odeh Es Hashem"*. The minute I heard those words, I knew that they encapsulated all that I wanted this Bar Mitzvah to be about. I knew we would walk into this *simcha* with joy and happiness! Of course, we all broke out into a joyous rendition of the song "Thank You Hashem." The song is so filled with joy and carries so much meaning and depth for us. Ever since that day, this song has carried us on its wings. Our family sings and dances to it and we feel the joy of this special occasion and our special boy.

It is said that every child is named with *ru'ach hakodesh*. *HaKadosh Boruch Hu* foresaw thirteen years ago why my son's name had to be Yehuda!

Once we had the theme worked out, we were able to move forward with the planning. There were so many decisions to make and details to decide. We debated if we should do Shabbos or a weeknight, undecided what would be better for Yehuda. I settled on a weeknight, as I wanted *everyone* to be able to come for Yehuda. We planned to set up a glamorous *vort*-style event in our home, where Yehuda would be the most comfortable.

We planned to set up speakers and a projector with a slideshow running continually throughout the night. We would play a speech that Yehuda gave via his I-pad, appropriate to his level. There would be a heartwarming song, sung by his brother, to the tune of "Thank You Hashem." As the beautiful words were sung, the slideshow would project photos of Yehuda in different stages of his life, culminating with photos of my husband putting *tefillin* on Yehuda.



Yehuda's Siblings

One unexpected challenge was his siblings' feelings about having Yehuda in the spotlight. I had not anticipated the anxiety and emotions this would cause my kids. All their friends were *schmoozing* about Yehuda, as kids tend to do, and it was not in a super-sensitive way.

A few days before the Bar Mitzvah, we went around to put the magnificent invitations into our neighbor's mailboxes. My son came home saying that the whole neighborhood was talking about it. Some boys could not get over that Yehuda could look so nice in the picture. Others wanted to know what Yehuda would do at his Bar Mitzvah. My daughter said everyone must think we are doing it in our house because he has special needs, and it's going to be really *nebby*…

We were planning for my girls to wear their beautiful Shabbos dresses. But as I watched their emotions and anxiety rising, my thoughts were that these kids needed to feel glamorous. They needed to be tall and proud, to feel confident for the moment their friends would say: "Yehuda grabs sesame chicken with his hands?" or: "That's the Bar Mitzvah boy? Where's his tie?" We started to look for new dresses, but the stores were cleaned out. The day before the Bar Mitzvah I took them to an upper-class store and spent way beyond anything I had ever before. Hashem sent us beautiful dresses! And the girls felt like a million.

On the day of the Bar Mitzvah event, I left my house at 4:00 with my girls to get their hair done; our emotions were running high. The hairdresser mentioned that she had baby's breath to put in my girls' hair, left from her sister's Bas Mitzvah on Sunday. I said: "You must do a very special job as it's for the Bar Mitzvah of a very special boy." She said: "Wow, we just had my sister's Bas Mitzvah in SCHI!" and I thought: "Hashem, how did You know just what my children needed to hear at this moment?"

Yehuda's Gifts

Once the invitations went out, friends and family started to call and ask what kind of presents Yehuda would enjoy. My heart filled with joy and I knew that we were doing the right thing. Everyone was taking out the time to focus on Yehuda, they were investing time to make him feel good. They were so creative, and Yehuda was so happy with each gift. One bought a *becher*, others brought linen, an airbrushed sweatshirt, mikes that sing music, comic books, nice picture books, a *Siddur Sheli*, a personalized towel, luggage, a stuffed character, a picture album, and more! It was amazing that everyone took the time out to think and give something special for our dear Yehuda. This gift-giving was a hug from Hashem; it was something we had not anticipated and it clearly filled Yehuda with joy.

Mazel Tov, Yehuda!

As I walked through the front door on the evening of the Bar Mitzvah, it was hard to believe that it was actually my house!

The rooms were transformed with the beautiful flowers, photos, and decor. We came in and were just overcome. This was an event fit for our special boy! Yehuda cooperated for pictures, a credit to his amazing *Morah*. I was waiting for him to lock himself in the study with his videos. Then people started coming, and they came in droves. At one point I looked into the dining room where the Bar Mitzvah video was airing, and it was wall to wall guests. Everyone came out for our special boy: teachers, therapists, relatives, and neighbors. Yehuda had touched the lives of so many.

Hashem came down to our Bar Mitzvah; the *Shechinah* was tangible everywhere. As I stood there looking at the crowds, I remembered our fears of bringing so many people together and worrying that it could be a time of tears, of looking at Yehuda's deficits and saying: *"nebach."* Well, we failed miserably in avoiding tears, as there were many, but they were tears of happiness, tears of connection to the *Ribono Shel Olam.* Tears are the language of the *neshama*. Anyone who attended Yehuda's Bar Mitzvah and watched the magnificent slide show cried. Their *neshamas* were touched by his special *neshama.*

To our astonishment, Yehuda HIGH-FIVED everyone, and even GAVE OUT SOME HUGS. HE DANCED WITH SIMCHA. At one point, I noticed him strutting through the men as if he owned the place. It was his *simcha* and he knew it. He was so proud and so happy.

Yehuda's participation was Hashem's way of telling us: "You only have to try, and I will do the rest. You opened a door so narrow, but I swung it wide open beyond your wildest dreams." We had wanted to display Yehuda in a positive light, but we really weren't sure if it would work out. Hashem took care of it all, as only He can, and the results were marvelous, beyond our wildest dreams! Anyone who was privileged to be there on that special night surely encountered the *Shechinah* itself.

We really appreciated all of the warm wishes that people wrote to us in honor of the occasion. Here is one of my favorites, from Yehuda's grandparents:

You were named Yehuda right from the start,
Thank You Hashem from the bottom of our heart.

You gave us the *zechus* to be connected
To a special *neshama* sent down to be perfected.

You accomplished so much in your thirteen years
Along with so much laughter, prayer, and tears.

Now B"H you're wearing *tzitzis, yarmulka* and a suit,
You belong to us, you look so cute!

You're lucky to have such a devoted father and mother
Doting aunts, wonderful sisters, and a *talmud chacham* as a brother.

You should be *gebentched* and give us all *nachas* galore
Keep smiling! There is more in store.

Together may we greet *Mashiach Tzidkeinu*,
Speedily in our days – *B'mihaira B'yameinu.*

Love, *Zaidy* and *Bubby* Dickstein

Imperfect *Perfection*

Yitti Berkovic

It is only a twelve-second video clip, but I can't stop watching it. I hit replay on my phone – again and again and again – swaying with the words as if they were a song: *"Baruch Ata Hashem, Elokeinu Melech HaOlam, Asher Kidishanu B'Mitzvosav Vitzivanu Al Mitzvas Tefillin."*

It is a rushed *bracha* – with some of the words slurred or skipped altogether – but it is a perfect *bracha* nonetheless, one that seems to emerge, not from his lips, but straight from his *neshama*. I am mesmerized as I hit replay. *Again and again and again.* It is a video clip, filmed just this week, of my son Naftali – my brand-new bar mitzvah boy – putting on *tefillin* for the first time.

It is an unconventional scene, unlike most bar mitzvah celebrations. My husband and son are standing in the corner of our dining room, and I and my cellphone are the only audience. There is no sponge cake or shot glasses on the table, no well-wishers or proud grandparents present. After endless debate, we decided not to invite anyone to join us. He is not ready. *We* are not ready. Instead, it is just us, my husband and I, holding our breath to see how he will respond to the stiff leather straps around his arm and his head, how he will react to the pressure of our expectations.

> *Would he have stood before a quiet shul and dazzled everyone with a melodious and error-free parsha leining?*

My husband works quickly and deliberately, wrapping and crisscrossing the *ritzuos* in the way they have been wrapped for generations, but in a way that is new and overwhelming for Naftali. Naftali stands and watches while I stand and watch, neither of us quite sure what his reaction will be.

We have been preparing for this moment for months. We have worked with his behavioral therapist to choose the right strategy, showing him pictures of *tefillin*, taking photos of the men in his life wearing *tefillin,* allowing him to select the prize he will receive when – *if* - he puts on his *tefillin.* There is a brand-new Lego set waiting on the table – maybe not the most typical gift for a boy turning thirteen – but that is what he asked for, and that is what he will be getting.

Still, I wait for Naftali to refuse. He has always been a sensory child, fussy about the fabrics and textures that touch his skin. When he refuses something, he becomes loud and aggressive – sometimes even violent. I anticipate that he will push the *tefillin* away, fight the straps when they are placed on his arms, reject the tradition that we so badly want him to embrace – or at least *accept.* This moment could be ugly and disappointing – or – *it could be beautiful.*

I get the camera ready anyway. Maybe, maybe, he will surprise us, and I will want to share this video with the many who love him but were not asked to attend. I wait. *He is not fighting. He is standing perfectly still. He is saying the words willingly.*

Without ever practicing the *bracha*, he somehow knows the words to say and when to say them. Even though he mumbles, each sacred word has an almost symphonic energy that tells me I am witnessing something that is not of this world alone.

His *neshama*, his *tafkid* on this earth, is compelling him to do a *mitzvah* he should logically reject. He should *hate* the restrictive feeling of the *tefillin* straps. He should *hate* being told to stand in one place. He should yell loudly like he often does. He should kick and flail.

But he is allowing it. *No,* he is embracing it. He is as proud of himself as I have ever seen. I can't help myself. I am smiling as I cry. I am crying as I smile. *I almost don't know what to feel.*

On most days, I don't allow myself to play the *what if* game. It is too seductive. It is too alluring to drift off into a parallel universe – a fantastical universe – where life unfolds exactly the way you dreamed it would. But playing the *what if* game can also be toxic.

Recently, I could not help myself. Two of my nephews, born within nine days of Naftali, had their bar mitzvahs this week. I celebrated those *simchos* with a warm, open, happy heart, so proud of my nephews for the men they are becoming. But as I watched them meet magnificent milestones – donning hats, putting on *tefillin, leining* from the Torah, delivering their *pshetels* – I let myself wonder.

What if Naftali had not been born prematurely? What if he had been born prematurely but had not had developmental delays? What if he had never been diagnosed with autism? What if he had been diagnosed with autism but would have been higher functioning or with fewer behavioral challenges?

Sitting at those *simchos,* I closed my eyes and let myself imagine: What would his personality be like? Would he have stood before

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On the Lighter Side...

You, Too, Can Be a Caseworker!

Moishy's Mommy

Sometimes, when people benefit from a specific occupation, it inspires them to pursue this occupation themselves. For example, I know of people who spent a lot of time in hospitals and were motivated to join the medical profession. I also know some special needs moms who became various types of therapists.

After my last phone appointment with a case worker for my son Moishy (from one of the government agencies, which shall remain nameless to protect the guilty), I was likewise inspired to consider changing careers. In case you've also had this deep yearning, but just didn't know how it works, I'll gladly share what I've learned thus far, so that you, too, can become a caseworker!

It's important to schedule the appointment in advance. And then reschedule a few times after that. The phone appointments to which I refer take place every three months. At the end of each phone call, we schedule the following one for three months' time. It has never once happened that we simply kept the originally scheduled time. I always receive a few phone calls asking me to switch the time, up to and including the day of the actual appointment.

It's ok not to keep the scheduled appointment. Even though you drove the client crazy with all of your phone calls asking her to switch the times to work out with your dog's grooming appointments, it's ok for you to call up to an hour earlier or later than the designated time. It is the client's job to sit in a quiet room beside her phone and be perfectly available, no matter if you are late or early.

Assume the client knows that her child must be present and next to her during the entire phone call. This one I learned the hard way. After calling me three times to reschedule, and then calling me 30 minutes late, my case worker sweetly asked: "Is Moshe present with you for the phone meeting?" When I answered in the negative, she said: "Oh well, then we will have to reschedule, as the patient must be present during the phone meeting." I tried to control my annoyance and said: "I have three things to say to you. First of all, in all of your phone calls, you never once mentioned that the client has to be present. Second of all, if Moshe was here, I wouldn't be able to speak to you normally because I'd be taking care of him. And third of all, he is in school every day until four thirty and you don't work past four. So, what would you like me to do about that?" To which she responded: "Yes, I'm sorry, we will have to reschedule."

The main purpose of the phone meeting is to determine if there have been any changes since the last appointment. A good way to accomplish this is to ask: "Have there been any changes in the past three months?" If the answer is no, you then go through every possible minute detail of their lives and ask about each one specifically.

Check for clarity. Be sure to stop every three minutes to ask if everything that you are saying is clear and if they have any questions. Offer to reexplain any and all possible topics relating to the client, even if they have nothing to do with the matter at hand.

There is no need to take note of the client's age and tailor the questions to be age appropriate. Just go with the script. That's why Moishy's case worker makes sure to ask me how many times a week he needs to go grocery shopping and if it's necessary for someone to accompany him. (Do you know any six-year olds, special needs notwithstanding, who go grocery shopping for themselves?!)

Offer your contact information. It's important that the client's family has a way to reach you (They don't have to know that you never actually pick up the phone or return calls). It sounds good to have a really long email address. When spelling out your email address, be sure to enunciate each letter clearly, giving an "N as in Nancy" add-on for each letter. This should take at least five minutes of the appointment time.

Ignore all background noise. Just continue with the phone appointment, even if it sounds as if the client's house is on fire (Remember, **you** insisted that the special needs client be home at the time of the phone call!). In our case, I rescheduled the appointment for Friday afternoon, as Moishy would be home from school earlier on that day. In the middle of my Shabbos cooking, the phone finally rang. I put it on speaker, and continued spicing my chicken. I was very impressed with my case worker's ability to forge on with our 45-minute conversation to the background sounds of the mixer, oven timer, my munching on a snack, kids talking, and baby crying. At one point, my daughter started laughing at the absurdity of the lady's voice droning in the background of the Friday chaos. She got me to start giggling too, which prompted Moishy to burst into hearty laughter. (He may be delayed, but he's sure got a sense of humor!)

Don't forget to ask if everything is calm and safe in the home environment. Ask the mom if she has ever felt that she is overwhelmed. It's important that she reassure you that everything is perfectly under control, and that she is, in fact, just sitting most of the day with her feet up, drinking coffee (Ignore the smoke alarm and the children screaming in the background and move on to the next question.).

Be sure not to hang up before you schedule the next appointment. Assure your client that the next appointment will definitely be taking place in person. Then, on the morning of the next appointment, you can call to tell them that due to Covid, appointments are still taking place over the phone. And then, if you really want to do it right, you can offer to reschedule.

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a quiet *shul* and dazzled everyone with a melodious and error-free *parsha leining?* Or would he have struggled – as tone-deaf as I am? Would he have been too shy or too nervous, insisting on only learning the *haftorah* or nothing at all?

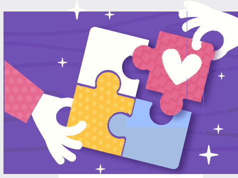
Would he have asked for a big celebration, relishing his moment as he danced in the middle of a circle of friends, or would he have been more introverted, craving a small *seudah* with only family? *What if Naftali would have been a neurotypical bar mitzvah boy? What if?*

But this moment that I keep replaying in my mind and on my cell phone helps quiet those *what ifs.* I can see in this moment that Naftali was never supposed to be someone different, someone else. He was never supposed to be like my nephews or like any of his typically-developing peers. He was given to us *exactly* how he was intended to be, with a purpose crafted precisely for him.

The commandment of *tefillin* requires the one laying them to bind heart, mind, and deed. I don't know what is in Naftal's heart. I don't know what is in Naftali's mind. But his deed stands as a shining testament to a *neshama* that is being perfected, no matter the imperfections of his *guf.*

His willingness to embrace this mitzvah – *so unexpected, so unlikely* – transcends the here and now, transcends our limited understanding of body and soul. Even if he does not have the words to tell me so, even if he has not had the typical celebration to commemorate it, I know that the impact of his brand-new *mitzvah* is shaking the heavens. *Mazal Tov!*

This articled was originally printed in The Voice of Lakewood.



Quality ABA:

What It Means to Your Child

Sara Miriam Pitterman

ABA, or Applied Behavior Analysis, is a mode of therapy used for clients with Autism. This column will explain ABA by providing a sample session to illustrate how the therapy is used.

Meet Yanky, a 17 year old with moderate level ASD (Autism Spectrum Disorder). He has been receiving services for years, but his therapy sessions have recently shifted towards job training, independent living, and community integration.

From Yanky's viewpoint:

"Today is Tuesday. That means Pinny is coming from 4:30-7 tonight, which is great because I'll get to go to the big *shul* on Main Street. When Pinny comes, the first thing we're going to do is make 'small talk.' Pinny says I don't need to tell him everything that happened, but just a little *shmooze*. I for sure will tell him about my sister Tzippy's new baby boy. Except he's not so new, and Pinny might say that he is old news. But I could say something new about him, like he just started to eat baby mush.

After we make 'small talk,' I'll go through my job checklist to make sure I have everything I need for work, like an extra pen, my cell phone, my wallet, and my employee ID. That's a new one that I just got from Joe Shmoe Supermarket, where I recently started working. I'll also take a look in the mirror to make sure I look like a Joe Shmoe Supermarket employee: "Neat, tucked in, no stains, and a smile." When we get there, I'll get to use checkout counter #15. 15 is my new best number. Really my checkout counter is not yet 'open for business,' because we are still doing practice runs.

After my 5-6:30 work shift, we are going to go to the Main Street *shul*, which is awesome. They always have orange soda in the fridge, which is my favorite. We used to go in Pinny's car, but now we started to bike. Pinny said when I learn the route and prove that I follow all the safety rules, then I can ride on my own. I'll be in *shul* for *Maariv,* and then I can choose if I want to stay and help out. That *shul* always needs help straightening up. If I want to, I can choose a chore. My parents want to help the *shul* out, so they give me $1 for each chore I do for the *shul*.

Pinny Cohen, RBT (Registered Behavior Technician):

I've been working with Yanky for 2 years now, but the session has changed so much over time that I still feel pretty fresh and enthusiastic. Here is a chart listing our current goals and some teaching supports that I use in my work with Yanky:

GOALS	SUPPORTS / PROMPTS
Build Conversation Skills (these are targeted areas Yanky needs to work on): • Sharing new information • Not repeating or perseverating on favorite topics • Refrain from sharing very personal information	**Before we start, these are some things I remind Yanky:** • Take a minute to plan what you want to share. Think about if I know it already. • Medical or bathroom information is for your parents only. • Small talk is just a chance to connect; it's not a long conversation, so no politics or COVID discussions.
Job Training (these are Yanky's Current Goals for his job at the supermarket): • Look presentable: We use a checklist mantra so the checklist can fade ("Neat, tucked in, no stains, and a smile"). • Scan items using barcode • Enter amount for multiples of the same item • Weight calculations for fruits/veggies • Build work tolerance - Yanky started with a 30 minute work shift and is currently doing 90 minutes. The ultimate goal is a 4-hour shift with intermittent supervision and support.	**Job Training Future Goals:** • What to do with items the customer decides he doesn't want • Giving change • Handling Food Stamps/ WIC/ Vouchers • Putting total on an account • How to bag: dairy, fridge items, milk/meat, eggs get their own bag, not making bags too heavy.
Independent Functioning: • Biking as a means of transportation	**Currently working on only one bike route.** • As Yanky struggles with directions, we want to practice until he masters one route before introducing a new route. • He will be picked up and driven home by his father.
Community Integration: • Joining for *Maariv* • Assist with *shul* tasks	**It's very important to Yanky's parents that he is accepted in *shul* and familiar with *shul* routines.** • They are paying him to do chores in *shul* so that motivation to give to the community is established.

Sara Miriam Pitterman is a BCBA, working in Lakewood, NJ for Brainbuilders LLC, an insurance-based ABA company.

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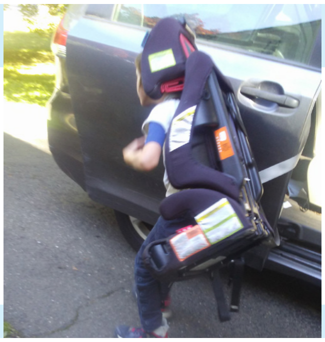
SNIPPETS

The escape artist does it again!



From the Doctor's Desk

Melatonin Supplementation

Yehudis Blavin, PA-C

Q: My daughter has difficulty falling and staying asleep, and people frequently tell me to give her melatonin. I generally avoid giving my children medication unless absolutely necessary. Is melatonin a medicine? Is it safe? Are there side effects? I'd love to learn more about it.

A: Melatonin is a hormone that is naturally produced by the body in response to darkness. It helps your body get ready for sleep and contributes to your natural circadian rhythm. The concept of melatonin supplementation is that having extra melatonin in your system can help your body get tired faster and stay asleep longer. The commercially available melatonin is synthetic melatonin hormone, at a dose higher than the body typically produces, used to augment the natural melatonin produced in your body.

Melatonin supplementation used on an occasional or short-term basis is considered safe and moderately effective, helping people fall asleep about 30 minutes earlier and stay asleep 30 minutes longer than they would have without the supplement. There are not many short-term side effects, and the ones that have been reported are not very concerning. They include headache, dizziness, agitation, increased bedwetting, and, obviously, tiredness. Melatonin can safely be recommended for times when sleep may be difficult, for example to combat jet lag or to help someone fall asleep before a big or anxiety-inducing event.

Taking melatonin supplements on a regular basis to promote sleep, especially in children, is more controversial. There simply aren't enough studies on supplemental melatonin's effects on children and their development when it is used for long periods of time. Because melatonin is a hormone, some question if long-term use can affect hormonal processes like puberty, menstruation, and prolactin production (a hormone necessary for lactation). Therefore, medical organizations like the American Academy of Sleep Medicine and the American College of Physicians do not recommend using melatonin supplements, stating that there isn't enough data to determine the effectiveness and safety of continuous use.

On the other hand, there is not enough evidence to say that long-term use of melatonin is significantly harmful either. To add to that, lack of sleep has negative effects too, and some children, particularly those with ASD (Autism Spectrum Disorders) or ADHD (Attention Deficit Hyperactivity Disorder), may regularly experience difficulty with sleeping, which can considerably affect the entire family's functioning.

Like so many aspects of medicine, using melatonin requires a risk-benefit analysis. How disordered is your child's sleep and how disruptive is that to your overall lifestyle? How well does your child respond to melatonin supplementation, which seems to work better on some children than on others? Because of the many factors under consideration, it is best to discuss your situation with your child's doctor to determine if the benefits of melatonin outweigh the potential risks for your particular child.

Yehudis Blavin is a Physician Assistant who specializes in internal medicine and surgery.

Please note: The Information expressed in this column is for educational purposes-only and should not substitute for the advice of your personal medical professional.

Do you have a medical question that you would like answered? Send in your question to Neshamale and we may feature it in a future article.

VALIDATION Corner

David Rose

♥ SAMAYACH B'YISURIM

For people, not for robots

Imagine witnessing the following scenario: A guy is running really fast, huffing and panting. Suddenly, he stubs his toe – hard! His face contorts with pain, as he hops up and down holding his black and blue toe. Suddenly, he starts dancing a jig, laughing and singing a jolly tune.

Do you think there anything off about this scenario? Why? After all, doesn't it say we're supposed to be *samayach b'yisurim* (happy with hardships)?

Perhaps we need to explore what *samayach b'yisurim* means at a deeper level. Many years ago, my father, *shlita*, shared with me an incredible, eye-opening idea. The *Gemara (Maseches Brachos* 60b) says that a person should make a *bracha* on good occurrences as well as bad ones. On good things, we say: *"HaTov v'HaMeitiv,"* and on bad: *"Baruch Dayan HaEmes."* Both, however, are equal in the instruction of *L'kabulin'hu b'Simcha* – one should accept both the good and the bad with happiness.

> ***After a person reflects on what happened, hopefully he will see the bigger picture and understand how it was the right thing.***

Rashi explains this to mean *"b'Leivav shaleim* – with a complete heart." He does not say to start dancing or rejoicing. Rather, a person should say the *bracha* that Hashem is *Dayan HaEmes*, the true judge, wholeheartedly. My father explained this as follows: Just as we easily credit Hashem for good things that happen, realizing that they are 100% righteous, so should we feel when bad things happen. In other words, *mekabel b'simcha* means when we experience a difficulty, we are meant to strive towards **accepting it; realizing that it is the right thing that's supposed to happen, and that it is from Hashem.**

The term *samayach b'yisurim* for many, erroneously conjures up images of a person going through a hard time entirely unemotionally, trying to be like a machine without a worry or stress in the world. This idea does not match what Rashi is saying. Where does *simcha* come in? After a person reflects on what happened, hopefully he will see the bigger picture and understand how it was the right thing. This can bring a person to tremendous, genuine happiness, appreciating Hashem's deep love for us and recognizing His involvement in our lives.

Make no mistake - this is not an esoteric concept for people on a low *madreiga*. We need no clearer proof than from Aharon HaKohen. When his two sons, Nadav and Avihu, died, it was a terrible tragedy. How did Aharon react? *"Va'yidom Aharon"*—with silence. This can be misleading; it seems as if he was emotionless: no crying, no tears, a machine. But the Ramban says just the opposite, that Aharon was wailing loudly, screaming in grief, inconsolable. It was only after Moshe comforted him and told him *"B'krovai Ekadeish,"* only then was it *"va'yidom,"* that Aharon quieted down. If Aharon HaKohen can have emotions, so can we! Hashem knows that we are human!

As the *Gemara* and Rashi say, we must have **acceptance**, realize it is from Hashem. Through accepting, we can connect and strengthen our relationship with Him, recognizing how He is truly with us. Working on this will lead to incredible happiness.

A family I know was having an extremely hard time dealing with a serious medical situation in the family. They called a certain organization and, after talking with them, the representative said: "We'll have to see exactly how we can help. But know one thing: you are not in this alone anymore. We are with you every step of the way." Hearing those words didn't make the family's difficulty disappear, but it was enough to make them feel as if someone was holding their hand, that they were no longer alone. The words gave them tremendous *chizuk*.

When we hear difficult news, *chas v'shalom,* or are going through a rough patch, it is natural to feel pained and abandoned. Yet, these are opportunities to be *samayach b'yisurim* – to remember that it all comes from Hashem. He is doing everything for our good and He longs for us to accept it all – not with robotic stoicism, but with heartfelt emotion, and a firm belief that it is all from our Father, Who loves us very much. We should hear Him saying to us: "Know one thing: you are not in this alone. I am here with you every step of the way."

Illuminations

BAR MITZVAH TIMES TWO

When my son was born at 24 weeks via a harrowing emergency C-section, no one expected him to survive for more than a day or two. He had been deprived of oxygen for a few crucial moments, and had suffered severe brain damage. Yet little Mechy was a fighter, and he pushed through the critical few weeks after birth.

"I'll be honest with you," said the neonatal specialist in the NICU, as my husband and I sat in his office, dizzy and exhausted, numbly awaiting the verdict. "Perhaps it would have been better if your baby hadn't survived. After all, although his heart is still beating, there is almost no brain activity. I'm sorry to inform you that your baby will remain in a vegetative state for the rest of his life."

The doctor continued to talk about statistics and the limits of modern medicine, but I was too frozen in shock and distress to absorb anything. Mechy was our fourth child and first son, a long-awaited baby, born when our youngest daughter was six years old.

I somehow stumbled out of the doctor's office and went downstairs to the lobby, where I began to cry. My sobs echoed through the sterile hospital corridor and brought a kindhearted volunteer to my side. "Don't worry, hon," the woman said, patting my shoulder and handing me a wad of tissues. "It will be okay."

But it wasn't okay; not then, and not for many years. Our baby remained in the NICU for months, and finally had his bris when he was just shy of a year, at which point the hospital wanted to discharge him. As they explained, they were not a long-term care facility and had no resources to take care of children who weren't compatible with life.

Our son, Michoel Yehudah, was named after my great-grandfather, Michoel. We added Yehudah because we wanted to express our gratitude to the *Ribono shel Olam* for our special gift, even if he was imperfect.

Mechy, as we called him, was on life support and in a vegetative state, which meant it was impossible to bring him home. My husband and I spent many hours on the phone, trying to find a home where our precious son would be cared for with compassion and dignity for as long as his pure *neshamah* inhabited his body.

We never beat around the bush with our children or withheld the truth. They knew that their baby brother was very sick and might never wake up or come home. Still, they loved him and visited him frequently in the NICU, talking to him and leaving adorable "get well" cards.

A few weeks after Mechy's first birthday, we finally found a hospice in upstate New York where our angelic baby would be cared for and cherished. After reams of paperwork and a prolonged battle with our insurance company, our baby was transferred to his new home, a nearly four-hour drive from where we lived.

We accompanied Mechy in the specially outfitted ambulette that transferred him from the hospital to the children's home. Although this took place many years ago, I recall every detail of that endless bumpy ride: the still, silent form of our baby lying peacefully in his crib, attached to one machine that monitored his heart rate, and another machine that supplied him with a steady stream of oxygen.

"Sleep well, my little *tzaddik*," I whispered, as the nurses tucked him into his new crib and reassured me that he would be well taken care of. We were welcome to visit as often as we wished, along with our children.

Our baby thrived in his new home, gaining weight and growing from a helpless infant into a small child. As the neonatologist predicted, Mechy remained in a vegetative state, his eyes unfocused, and his movements sporadic. As the years passed and we merited another two sons, I continued visiting Mechy every few weeks, sometimes alone and sometimes with some of our children. It was heartbreaking to watch him writhe and make incoherent sounds, his *neshama*'s way of reaching out and letting us know that he was there. I spoke to him often, sharing how much we loved him.

It was harder for my husband to connect to Mechy, who was locked into his own world. He visited far less frequently, since, as he expressed, "It doesn't matter if I'm there or not; Mechy has no idea who I am."

"Of course he does!" I said. "When I am near him, his breathing is steadier and he seems so much happier. I'm sure he senses how much we care." Over the years I remained his primary visitor. I brought gifts to the nurses regularly and lavished them with praise, knowing that it made a difference in how they cared for my son.

Shortly after Mechy turned 12, I started planning his Bar Mitzvah. I knew better than to mention it to family members, because they would just shake their heads and accuse me of living in la-la land. But I wasn't just dreaming. True, our Mechy would never have the opportunity to accept the yoke of *mitzvos* and to wear *tefillin* on his head and arm. Yet that didn't mean he couldn't have a Bar Mitzvah or merit the *zechus* of *tefillin*.

Late one night, as I tossed and turned, Hashem sent a brilliant idea into my head. What if we found a young boy who was turning Bar Mitzvah at around the same time, whose family was desperately poor and could not afford *tefillin*? Perhaps this Bar Mitzvah *bachur* would be willing to share his *mitzvah* with our Mechy, and it would be a *zechus* for both boys.

My husband didn't understand my enthusiasm. "Mechy is exempt from wearing *tefillin*. His *neshama* is pure, like that of a newborn baby. What are you trying to accomplish by making him a mock Bar Mitzvah?"

"Please do it for me," I begged. "I know it's not rational, but it will make me feel better."

My husband agreed, if only to please me. I called a local community *tzedakah* fund and asked them to help me find a candidate – a family struggling financially with a boy who would be Bar Mitzvah in the summer.

A few days later they got back to me with a list of five families, all of whom qualified, with boys around that age. I did some research and decided to offer the opportunity to Uri Ben-Shimon (names are changed), a boy who lived with his mother and siblings in a cramped, decrepit apartment. Uri's father had left the family years ago, and they were struggling to get by. I was stunned to learn that Uri's Bar Mitzvah was the same week as Mechy's.

I visited Uri and his mother, Yonit, in their small apartment, and explained what I had in mind. Although Yonit, who worked as a babysitter, was thrilled with the idea, her son needed some time to think it over. I offered to drive them to visit Mechy and perhaps forge a connection with him.

Two weeks later, I drove Uri and his mother to the group home facility where Mechy lived, and where the Bar Mitzvah would take place, as our son could not be moved out of the home. Uri was silent for most of the ride, and hung back as we entered Mechy's room.

"Good afternoon, Mechy," I said, lightly tapping his arm. My son's eyes fluttered open and he made a guttural sound. I saw Uri flinch, but quickly compose himself. He stood next to Mechy's crib and gazed at him in silence for a few moments. Then he nodded.

"I'll do it," he said. "I want to share my Bar Mitzvah with Mechy." He agreed not only to share his bar mitzvah, but also to undertake the tremendous responsibility of putting on *tefillin* every morning for the rest of his life, not only for his own *zechus*, but for that of my son.

We spared no expense, ordering a *mehudar* set of *tefillin* for the Bar Mitzvah boy, written by a respected *sofer.* After obtaining permission from the directors of Mechy's home, I booked a caterer and party planner to host a party. I explained to the directors and staff the significance of a Bar Mitzvah—that this would be my son's rite of passage, so to speak, as he becomes a Jewish adult.

The directors, nurses, and quality-of-life personnel were very accommodating, and worked with us to clear the calendar and make a large room available. As the grand day drew closer, I invited my extended family and friends, as well as Uri's entire family. Unfortunately, Uri's estranged father refused to attend.

I was a bundle of nerves as we got dressed and drove upstate to Mechy's bar mitzvah, the only milestone he would ever get to celebrate. When we arrived, I was moved to tears at how much effort has gone into the event. The staid recreation room had been transformed. The party planner had gone all out, ordering exquisite floral arrangements to match the black and mauve décor. I had hired a one-man band and singer, and invited an inspirational speaker who would address the two Bar Mitzvah boys.

The event began at 7 p.m. with a beautiful song, composed especially for the double Bar Mitzvah by a popular singer who cleared his calendar and graciously joined the *simcha*. There wasn't a dry eye as my husband spoke, emotionally thanking Uri for agreeing to undertake the sacred charge, and doing it with such maturity and goodwill.

"Mechy is a pure *tzaddik* who has never sinned, yet he cannot fulfill any *mitzvos* on his own. By wearing your *tefillin* every morning and generously sharing your *zechus*, you will be bringing his *neshama* to *shelaymus*, and you will become elevated as well," my husband said. Uri smiled through his tears.

> *"I will always share a powerful bond with you, and promise to cherish these tefillin for the rest of my life," he said.*

The band then began playing *Elokai Neshama* as Uri stood next to Mechy, who was propped up in a wheelchair, an angelic figure wearing a white shirt, black pants, and a yarmulke on his head. Although he was normally restless and needed to be suctioned frequently, he remained calm and relaxed all night, his face glowing.

Uri then wound the *tefillin* straps on our son, addressing Mechy directly and calling him his soul brother. "I will always share a powerful bond with you, and promise to cherish these *tefillin* for the rest of my life," he said.

The nursing staff who cared for Mechy were very moved and thanked us for giving them the privilege of hosting this memorable rite of passage. For a long time afterward, I was on a high, grateful I had been able to give my son this *zechus*. Although the Bar Mitzvah had cost more than our other *simchos* and had taken months of planning, it was well worth it.

A year passed, and Mechy turned 14. I hadn't had any contact with Uri or his family in all this time, but one day I heard a speaker at a *shiur* dedicate her talk as a *zechus* for Yonit, Uri's mother, who was in the hospital with stage 4 cancer. I was devastated, and immediately went to visit her.

I was stunned to see Yonit, a once-vibrant woman, now emaciated and ashen. She recognized me right away, although she was very weak and didn't have strength to speak. I spent some time with her, thanking her for agreeing to have her son's Bar Mitzvah at the home, for sharing his special day with Mechy. She rewarded me with a sad smile.

Four weeks later, she was *niftar*, leaving her four young children rudderless and adrift. I heard that the younger children were sent to foster care, while Uri went to live with a distant relative. I *davened* for him all the time, but didn't know how to find him. "You know that Uri is struggling with his *Yiddishkeit*," a mutual friend told me one day. "Since his mother was *niftar* he hasn't been the same. I'm not sure he keeps *mitzvos* anymore."

No, I hadn't known, and was devastated. I had entrusted Uri with a sacred responsibility, asking him to put on *tefillin* for my son's merit. He promised me he would never neglect his obligation. Was he still putting on the *tefillin*? Was he *shomer Shabbos*? Did he sully his soul with nonkosher food? I had no idea, and on some level I didn't really want to know. I couldn't blame him, of course. He had been through more pain in his short life than most adults I knew.

During the next few months I redoubled my *tefillos*, begging the Father of orphans to have compassion on both boys, and bring Uri back to a Torah way of life, both for his sake and for Mechy's.

I was at the supermarket late one evening when I noticed a tall young man, wearing jeans and a sweatshirt, stocking the shelves. He looked somewhat familiar and I approached him hesitantly. To my surprise and delight, it was Uri – and he was wearing a *yarmulke*.

"Uri!" I said. "It's me, Mechy's mother. How are you?"

"Uh, I'm fine," he answered with a shy smile. "How is Mechy?"

"The same. I'm sorry about your mother. I felt very close to her. She was a pure *neshama*, a real *tzadaykes*."

The smile disappeared from his face as he nodded.

"Uri," I said, talking quickly before I lost my nerve. "I, uh, wanted to know about the *tefillin* we ordered for you. Are you still wearing them?" I waited tensely for the response.

"Of course I am," he responded. "I made a promise to Mechy and I won't ever let him down. Even in my hardest times after my mother's *petirah*, when I didn't know what to do with myself, I never stopped putting on *tefillin*."

"I'm so happy to hear that," I whispered, my voice choked up. "I'm so grateful, Uri."

"It hasn't been easy for me, to be honest, but stopping just wasn't an option," said the brave young boy. "Sometimes I thought about just leaving it all behind, going off on my own, but then I remembered Mechy and my promise, and I said to myself: "I can't disappoint him." So here I am. I'm on a journey and things are hard, but a promise is a promise."

It's been a few years now and Uri is doing well. He's still living in the community, working by day and learning at night. I keep in touch with him and help him financially, and we invite him for Shabbos from time to time. Uri's journey is our journey; I sometimes wonder if my Mechy came into this world to live a pure and sinless life so that Uri could find his footing.

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Activity Time!

Chayala Tawil

Water Balloons!

A water balloon is probably one of Avrumi's favorite toys in the whole world! Water balloons are generally enjoyed by all ages and stages, so it's a great family activity that he can participate in. Here are some original ideas for playing with water balloons, great for when you want something different than the classic water fight or "throw it back and forth" activities. Swim suits recommended!

Water Balloon Basketball

What you need: A bucket of water balloons and a kiddie-sized basketball hoop. (It can be a real one, a stick-on hoop from the dollar store, or even a simple bucket.)

Activity: Children try to throw the water balloons into the hoop to make a basket.

Musical Chairs

What you need: Chairs set up in Musical Chairs style (two back-to-back rows), music, and a bucket of water balloons

Activity: Play the classic game of Musical Chairs, with the added excitement of having a water balloon waiting on each seat.

Variation: Although musical chairs is usually played in a group, if you have only one or two kids, you can still play. Just tell them to run and sit on their chair when the music stops.

Wet Potato

What you need: Water balloons and music

Activity: Have the children sit in a circle and turn on your favorite music. Have them pass the water balloon to the next player, around and around the circle, until the music stops.

When the music stops, whoever is left holding the water balloon is out—and they have to break the water balloon over their head! You can keep playing until you have just one person left – that's the winner!

Variation: You can also play this with one child. When the music stops, they pop the balloon!

Water Balloon Pop Race

What you need: A hula hoop (or chalk) and water balloons

Activity: Line up the children against a wall/fence and set up hula hoops on the ground across from each child (or draw circles with chalk). Place a water balloon in each hoop. When you give the signal, each player races to their spot and sits on the water balloon to pop it, then runs back. Whoever does it the fastest is the winner.

Water Balloon Pinata

What you need: This one takes a bit more preparation than the others, but it is really fun! Prepare a bunch of large water balloons (if you can't find large ones, try using regular balloons filled with water). Tie a ribbon across two trees or poles outside. Attach the balloons hanging from the rope.

Activity: Children try to hit the balloons with a stick, and get a little shower!

Water Balloon Roll

What you need: Water balloons

Activity: Have the first person roll their water balloon as far as they can. Then it's the next player's turn to give it a try. Whoever rolls their water balloon the farthest wins.

Variation #1: Water Balloon Toss:

Children play the game by throwing the water balloons – whoever can throw the furthest without breaking their balloon wins.

Variation #2: Water Balloon Bowling:

Set up some objects to knock down for a bowling game. You can use empty bottles, blocks, or anything that can stand on its own and potentially be knocked down by a rolling water balloon.

Water Balloon Clean-Up Race

What you need: A trash can and cheap prizes or nosh

Activity: After all the fun, there are sure to be lots of colorful little pieces lying around your yard. Besides looking unsightly, these can be choking hazards. Make the cleanup process into a game! Tell everyone they get a point for every balloon piece they pick up, then award prizes or nosh to all your helpers.

WOW! MOMENTS

compiled by Fraydel Dickstein

Midwinter break is a really hard, often seemingly impossible time to find coverage for our special *neshamales*. I was nervous about coverage for Friday and Monday, and I just didn't have a head to find people. Then, a therapist texted that she was studying for her BCBA license and asked if she could use our daughter Chaya for a presentation and hours...she wanted to do three hours on both Friday and Monday—*Hodu L'Hashem!*

There was snow predicted for the Shabbos of midwinter and I was nervous about having everyone locked inside for a whole Shabbos. One hour before Shabbos, my niece called to invite my six year old (typically developing child) for Shabbos. She wanted to have a sleepover! This changed our family dynamics and we had such a calm Shabbos!

Then Hashem showed me even more how much He loves me! Sunday was still unscheduled, and I was sure none of the volunteers would show up. At 1:30, to my shock, the *Lev with Love* volunteer showed up, and at 3:30, before Chaya even got home, the next one came—*Mi k'Amcha Yisroel!*

Another angel called to take Chaya before the last shift even ended, and she returned her bathed and ready for bed—a gift wrapped from Hashem!

I felt Hashem's love so strongly! My husband always says don't worry, *Hashem Ya'a'zor,* and how right he is!

* * *

My son's therapist had some questions regarding my son's vision issues. I tried to get answers for her from the doctor, but the therapist was still not clear on exactly what my son was able to see and how to best set things up for him in school. She offered to come along with us to the next eye doctor appointment.

I told her that the next appointment would be on a Thursday afternoon, and it was about an hour's drive each way. I was sure she would back out, but she didn't. She simply showed up at the appointment, asked the doctor all of her questions and got the clarity that she needed to help my son.

When she left, the doctor turned to me and said: "That was amazing! Your son's therapist is so devoted. I have never seen anything like it!" A Wow! Moment, indeed.

* * *

During a rare quiet moment, I was lying in bed with my six year old. She started to tell me about all of her friends. "This one has tons of toys; this one is so lucky because she always goes on trips…" And then she added: "But we are much luckier!"

When I asked why, she looked at me as if I was slow and exclaimed: "Because we have Yehuda!"

* * *

The Children's Center in Lakewood makes the most incredible *Shabbaton* every year for *Shabbos HaGadol*. It's an unbelievable *chessed* and respite for us all. But that Shabbos, when Yehuda was away at the Shabbaton, we kept having mishaps. First, the fish burnt. Then the next attempt just didn't come out right. Then we had delicious soup, but the kreplach in it were spoiled.

My son got up and said: "That's it - we need Yehuda back! Everything goes wrong when he is not home!" Music to my ears…..

* * *

My daughter was waxing on and on about Chani and how terrible it is she is not normal, how crazy it is when she empties everything, runs around undressed and dumps things, how we have no games left, and on and on…

I was biting my tongue, as this was very painful for me to hear about my gorgeous, delicious *tzadekes* of a girl, but I figured it was wise let her get it all out…

As her tirade was finally drawing to an end, she launched right into: "…and that's why I like to take out other special needs kids—not because it's easy, but because I know it really makes a difference, and I know I am really helping them!"

* * *

Ahuva, a high school girl, called me up, asking me if I was planning on sending my son to sleepaway camp, as she wanted to work with him in the summer. I answered that he wouldn't be going to camp, and added that she was always welcome to come help me at home. I didn't think that was exactly what she had in mind, especially since she lives on the other side of town.

But the very next week she showed up at my door! She came on the bus straight after a full day of school, and took Avrumi out to the park for over an hour. He was so excited! I underestimated the love and devotion that Jewish girls have for our special needs children.

13 THE BAR MITZVAH:

A Special Simcha for a Special Boy

My Son

Milaine Grossbard

You came in this world, my son, and gave us so much joy.
Your future flashed before my eyes, my dear sweet baby boy.
A quiet, passive baby, how easy you were at first.
I thanked G-d each day for this amazing child I had birthed.
But things started to get difficult, not easy for you as they should be:
Walking, talking, responding to us, were stages we just didn't see.
We tested you for hearing loss; we worried you might be deaf.
The test ruled out disabilities, until only one was left.
G-d created you with Autism, a fate that made me weep;
I struggled with the pain and shock, the sadness was so deep.
But then your father said these words, and it penetrated my heart, dear son:
"Thank you, Saadia, for being my child—I wouldn't trade you for anyone."
These words shook me to my very core, they made me realize
That we can't choose our family, or the color of our eyes,
But I can choose to appreciate each gift that is given to me—
My dear Saadia, you are special, it's as plain as day to see.
The Autistic bubble you are in, makes each second hard to deal—
You're so wrapped up, that we forget, sometimes, how much you feel.
Your soul is ours to care for, you have a purpose here on earth.
While we're not privy to the reason, we know every soul has great worth.
So now it's your Bar Mitzvah, you turn thirteen years today,
Though it won't look like other Bar Mitzvahs, our great thanks to G-d we'll say,
And thank you, son, for giving us the gift of Faith that's unwavering,
And thank Hashem for sending Angels for protection—you they're favoring.
Saadia, you haven't words to speak, yet you can say "Amein!"
You try your best on Shabbos from your IPad to refrain.
You love to cuddle and to be held, even as you grow taller than me,
You try to show me your wants and your world—what you hear, and what you see.
You try not be a burden to me, or bring me too much stress,
So you help yourself to things in the cupboard (although it makes a mess!).
You try for independence, and sometimes it's really great,
Other times, your angels need extra eyes, to make sure that you are safe.
I am just an average mother, making rules up as I go,
Sometimes my answer to you is "Yes," but lots of times, it's "NO!"
While I don't know what the future holds for you, my darling son,
Thank you for being my Saadia—I wouldn't trade you for anyone.

Mazal Tov!

It's a Special Bar Mitzvah Celebration!

Compiled by C. Tawil

Gedalia 13

Eretz Yisroel

Gedalia has epilepsy and very severe learning disabilities, along with emotional/behavioral challenges.

We had a beautiful Bar Mitzvah *seuda,* even though it was during Covid and family could not come in from overseas. We made sure to have live music (which is not a given in *Eretz Yisroel*, where we live,) because that is something he would appreciate. We chose to have a *seuda*, as opposed to the usual *kabbalas kahal* (*vort*-style event) that is usually done here, so that there would be less unfamiliar people wanting to shake his hand and ask him questions.

My husband prepared a *d'var Torah* with him so that he should have the feeling that he said a *drasha*. We told him that after he says the first sentence everyone would start singing, so he shouldn't worry about knowing it perfectly. He started out saying: "It says in *Gemara daf....*" and everyone sang him down.

My husband prepared him to have an *aliyah* on Shabbos (it took a lot of practice to get the *brochos* right) and he actually did it and felt good about it!

Though we were very nervous about how it would all work out, Baruch Hashem, the Bar Mitzvah was beautiful and I think he will always have good memories of it as a joyful event!

Chesky 13

Lakewood, NJ

Chesky has a lot of medical issues and is considered low-functioning. We didn't see a point in making a public affair out of his Bar Mitzvah and we opted to go with an intimate family Shabbos instead. All of Chesky's siblings gathered in our home for a beautiful Shabbos together.

Throughout Shabbos, we took turn speaking about Chesky, the things we loved about him and the effect that he'd had on our lives. We reminisced about so many parts of Chesky's life – some funny, some scary, some happy, some sad (There are some caregivers that you just never forget!). It was a real family bonding experience.

We played a game in which everyone had to answer questions related to Chesky, such as: "What was your most embarrassing moment with Chesky?" As the mother, I heard things from my children that I had never even known, as they expressed what it meant for them to grow up with a special needs sibling.

Spending an entire Shabbos in this way was very therapeutic for all of us. We came away feeling grateful for our family, closer to one another, and closer to Chesky. I think that counts as a *simcha*, as well!

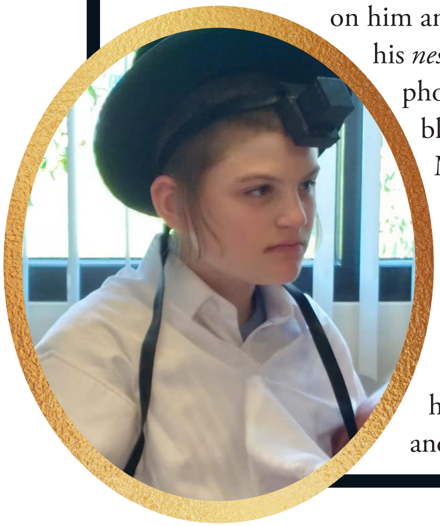
Mendy Herskowitz - 13

Brooklyn

Mendy is autistic, not on the higher functioning spectrum, but on what they call the 'severe' end. He is not verbal and has lots of difficult behaviors, what you would call a 1:1 child. He is also bright, charming, and very smart. When he was 8 years old we did the most difficult and bravest thing a parent can do for their child, and placed him in the Anderson Center for Autism. We miss him every day; but what Anderson has done with him makes it all worth it.

When Mendy's 13th birthday was approaching, we had to decide what to do. Obviously he wasn't going to have a real Bar Mitzvah. Parent of special needs kids have done all kinds of Bar Mitzvahs - the loud party ones with the *tantzers,* a *hachnasas Sefer Torah* instead of a Bar Mitzvah, a small quiet party with family and friends, etc. But with Mendy living far from home, not tolerating too much stimulation, and not having seen any family members aside from his parents and siblings (and occasionally his grandmother) for years, it didn't make sense to do an actual party.

Instead, my husband and I and our 7 year old son (my other is in yeshiva) visited him at Anderson. What took place there astounded me. My husband had quietly packed a white shirt, a pair of *tzitzis*, a black hat, and his own *tefillin* – hoping to put it all on Mendy. I prepared myself for a big physical fight - no doubt he would rip it all off - but to our astonishment he sat there quietly and cooperated, letting his father put all the garments on him and wrap the *tefillin*. The atmosphere in the room was otherworldly - it was as if his *neshama* was telling him to relax and embrace the moment. I stood there snapping photo after photo; I just couldn't believe we actually had Mendy sitting there in a black hat and *tefillin*, even though it was for a very brief few seconds. My husband put Mendy's hands on his eyes and said *Shema* with him. It was very special.



While this wasn't the Bar Mitzvah we envisioned 13 years ago, it surpassed anything we could have imagined five years ago. We feel very blessed, and thankful to Hashem. No, Mendy won't be doing any of the *mitzvos* of an adult male, but there is so much to celebrate. He has turned into a well-adjusted and happy young man, thanks to amazing folks at Anderson. If someone would have told me, back when we sent him to live at Anderson and I was so heartbroken, that five years later he'd be toilet trained, neat and clean, tall and lean, healthy and happy—I would have been thrilled. Boruch HaShem! It's a *simcha!*

Yehuda — 13

Brooklyn, NY

Our son Yehuda is obsessed with music, so we made that the focus of his Bar Mitzvah celebration. We had some special singers come, who were attuned to Yehuda's needs throughout the event. We had a small stage set up especially for Yehuda, on which he sang the night away on his own microphone. He loved being up there, and it also took care of his anxiety in crowds and his need for his own space. The Tanzers, (a volunteer entertainment group), came in to bring some extra *simcha*, and they really added to the excitement of the occasion.

Yehuda can't sit through an entire Shabbos *seudah* without getting antsy, so we had to arrange things to keep him with the program. We had two-minute speeches interspersed with the music, and had a buffet-style meal instead of a sit-down dinner with courses.

My advice to other parents is plan, plan, plan—and then expect the unexpected. No matter what, something will go off schedule. Still, there's beauty in the unpredictability of a special needs child; you just gotta go with the flow.

Shalom Noach — 13

Eretz Yisroel

When people ask me if Shalom Noach was overwhelmed by his Bar Mitzvah, I have to laugh. Shalom Noach has Williams Syndrome, which comes along with a super love of all people, crowds, attention, and excitement. He thrives in social scenes, so, no, we had no problem with that aspect of the event!

We made a much bigger Bar Mitzvah than we will probably make for the other children (we figured he doesn't have *that* many *simchos* in his life to celebrate, so we wanted it extra special for him), and it kept growing even bigger and bigger, as more and more people excitedly told us that they were coming. I think in the end, the entire town showed up, including the mayor!

We realized that a lot of the people were coming out of curiosity, or because it's cool to talk about "that Bar Mitzvah I went to last night for a child with special needs—it was sooooo emotional…"—so we just decided not go down that route, although it's easy to fall into that rut. Instead, we focused on the many people who came, at least some of whom were truly happy for us, and watched how much Shalom Noach himself was enjoying it.

It was set up as a beautiful "typical" Bar Mitzvah, along with some extra special touches that Shalom Noach really appreciated. One guy came in with a clown costume and made things *leibedig.* My brother in law, who volunteers for *Hatzalah*, surprised Shalom Noach: during the Bar Mitzvah he called him outside, and there was an ambulance waiting to give him a ride. That was HUGE for him! Of course, there was music, and everyone danced up a storm.

I think that that sense of "it's a Bar Mitzvah of a child with special needs," as much as it can be uncomfortable, also makes the guests less inhibited. They don't have to be as proper and formal as they might otherwise be. There was this free explosion of *simcha* and everyone just let go and danced away like anything!

I do think that a lot of it has to do with the way my husband invited his friends (who are also Shalom Noach's friends!)—very naturally, not making it into this dramatic (or even painful) affair. I mention this because I did see others inadvertently approaching this as a "heavy" event, almost a sad one, that you need to work hard to make happy. Although it's totally justified to feel that way, we really have a choice of whether we want to focus on what this simcha *isn't*, or what it IS. We didn't compare it to other boys' Bar Mitzvahs, and simply celebrated *this* special boy and the years behind him. We don't *have* to think and dwell on the missed opportunities. Obviously, it's not something a person can just tell themselves "don't do this"—it's lifelong work!—but it's a reminder to try to focus on the parts of the *simcha* that are happy and uncomplicated, and the guests will take their cues from us.

A friend of mine, whose son is severely autistic, added a beautiful letter to their Bar Mitzvah invitation, expressing very candidly what they want the guests to do or not do (ie: "If you see him doing XYZ, this is just his way of showing his excitement. He loves it and we all appreciate when you simply accept it and move on."). They also explained that even though their son can't show it, he does understand who's there and appreciates their attendance and "*Mazal Tov!*"s, and that they are bringing him so much joy. I thought that was amazing, and the results showed; he had a *simcha* no less happy and joyous and *natural* than Shalom Noach did. They also included a few ideas for gifts that would make him happy.

In our case, I felt it was so thoughtful when people called to ask us what they could buy, instead of groping in the dark and then either getting something completely irrelevant like a *sefer*, which was awkward for both sides, or trying their best and getting a *sefer with illustrations*, which was still irrelevant and a pity. Those who asked were so sweet and natural—we loved it! Not that we had too many ideas (although we could tell them that a can of Coke is the epitome of Shalom Noach's dreams!). Some of his favorite presents included a remote-control car with lots of music and lights, and a huge container of gumballs (which he finished in three days!) These simple and uncomplicated gifts were so thoughtful and moving—these people truly thought about HIM and were willing to think outside the box to make HIM happy!

(All the gifts were appreciated, of course, just not everyone knew how to go about it. That's why I thought my friend's candid preparation to their guests was so brilliant.)

Eli Charloff

13

Lakewood, NJ

We decided that Eli (who has autism) would be overwhelmed by a night Bar Mitzvah party (when his older brother had one, after five minutes he was begging to go to the car). We did not want to torture him on his big day, so this is how we celebrated: We bought each of my three boys big presents, something that they really wanted. We told them it was from Eli, in honor of his Bar Mitzvah, and it's because they help take care of him.

Then we set up a table in the house with lots of exciting nosh and toys on it and invited only a few people for a short amount of time, so as not to overwhelm him.

Eli had a class party in school, as well as in his respite program, which was not attended by the family. One girl offered to take photos of him by the lake (at the end of the photo shoot, he landed in the lake for a bit—never a dull moment!). Angels (some of the special girls who have helped us with Eli) took him for Slurpies on the way home.

There is a level of acceptance that must come along with each new stage that we reach. It's not easy, but Boruch Hashem, we have worked through it. We are waiting for the *Geula,* when we will be reunited with our son as a healthy, regular person. We know he will thank us and all the others who helped us raise him.

This is what I wrote when I sat down to try and plan Eli's Bar Mitzvah:

13 reasons to celebrate My Eli's Bar Mitzvah

Things I am thankful for:

1. I am still sane (or at least I think so!)!
2. Meeting such kind angels who help me and show me kindness I never knew existed.
3. Friends who show me I'm not alone. They just get it, without my explaining.
4. For the chance to do *chessed* every day. The constant giving makes me into a stronger, kinder, better person.
5. That Hashem thought so highly of me and my family.
6. The Special Children's Center that is there for us.
7. For a wonderful husband who puts up with so much craziness.
8. For a big backyard, so Eli can have lots of space to run around.
9. For a close friend who welcomes me into her home Shabbos mornings and is so kind to both of us.
10. For my other kids, who accept Eli and help me take care of him.
11. That I lived through Corona, and managed Eli, even though it wasn't easy.
12. That Hashem's ways are good, even if we don't see the full picture.
13. That Hashem made Eli exactly how he should be, and he is perfect the way he was created!

Yisroel

13

Monsey, NY

Yisroel (who just turned 30, hard to believe!) had a beautiful Bar Mitzvah. Although he has Down syndrome, we had a fairly typical Bar Mitzvah. We were living out of town at the time, and many of our relatives came in for the event. I don't think they knew quite what kind of simcha to expect, so we included a poem with the invitation in which we expressed our feelings. We thanked everybody for all of their help in the past, and let them know that we would be celebrating this Bar Mitzvah with all of the joy and significance that it deserved. Our relatives reciprocated by penning heartwarming wishes, poems, and letters, and putting them all together into a book, which we treasure until today.

Yisroel had an *aliyah* to the Torah, and was able to make the *brachos* and give a speech. The meal and the dancing were *leibideg* and full of *simcha,* just like any other Bar Mitzvah would be. In general, we've always treated Yisroel as normally as possible, expected a lot from him, and didn't spoil him.

Yisroel absolutely loved his Bar Mitzvah. He is a real people person, and being surrounded by all of his friends and family was the most exciting thing for him. He truly felt like a million dollars!

Here is the poem that we sent with the invitation:

YOU ALL HAVE A PART
When our baby was born, with his muscles so weak,
His whole future, and ours, seemed so terribly bleak.
But from our baby, whose muscle tone was so low,
It's unbelievable to see how much he learned,
And how much he forced us to grow!

There were so many lessons for us to learn;
In Hashem's kindness, He sent us a network
Of friends and relatives to whom we could turn.
So many steps in development, it seemed so out of reach,
The list was endless, way too much to teach.
So Hashem sent many wonderful people,
Who helped him throughout all his years.
They helped us too, in so many ways,
With our fears, as well as our tears.

Whether they taught him red, yellow, and blue,
Or how to read, or write, or tie his shoe,
Whether they said Tehillim, or helped financially,
Did mitzvos in his zechus, or drove him to therapy.

Whether they worked for Keshet, a great institution,
Or if they support Keshet with a generous contribution.
All of you have a big part
In helping our son reach this milestone.
Thank you from our heart,
We couldn't have done it on our own!

Thank you to the parents of Chesky, Gedalia, Eli, Mendy, Shalom Noach, Yehuda, and Yisroel, who took the time to talk and/or write about and share their experiences.

Tips From The Experts

hey! that's us!

My daughter is eight years old. She has special needs and attends public school. She's always so left out of things at home, because she doesn't learn at Bais Yaakov with her sisters. I'd love to hear ideas from others about how to bring Torah and Mitzvos into her life.

(Editor's note: We are expanding this question to include ideas of how to bring Yiddishkeit into our children's lives, regardless of age or ability.)

The question is whether it really bothers your daughter, or if it bothers *you* (her parents). If it really bothers her, then of course she should be learning more, so she can feel more "in the know." This can be done by the parents themselves, by other siblings, or by a *chessed* girl. On the other hand, if it's really the parents who are bothered by her lack of learning Torah, you should understand that every child has a different *tafkid* and a different Torah to learn. You need to concentrate your efforts on making her days full of whatever she needs, to be healthy, happy, and productive.

Shira M.

Your daughter's feelings are important, and it's also important for her to know more about her heritage. A parent or tutor should teach her about Judaism after school hours, on whatever level is appropriate. Start with the Hebrew *Aleph Bet*, and Shabbat and the Holidays.

Judy D.

Every morning when I wash my son's hands for *negel vasser,* I try to think: "We are washing off the *tamai* water so that he can serve Hashem today." I have in mind that his whole day of living the (challenged) life that Hashem gave him is a *mitzvah* in and of itself.

Although there aren't many *mitzvos* that our son can do, we try to look for opportunities, such as kissing a *mezuzah* or sharing his toys. I try to *daven* out loud next to him, and have in mind that he is *davening* "with" me. We try to put a *yarmulke* on him, even for a few seconds, and include him in exciting *mitzvos,* such as shaking the *lulav* and *esrog,* smelling the *b'samim* at *Havdalah,* dancing on *Simchas Torah,* etc.

C.T.

After-school programs can be the answer to the public school dilemma. Most do teach the *aleph bais* and about *yomim tovim* there. You can also request topics that you want your daughter to learn about there. It's important to ask them to let you know what they are teaching, so that you can talk to her about it at home.

Also, play CDs such as Rabbi Juravel and Uncle Moishy. They are very entertaining and contain a wealth of information about Shabbos, *Yomim Tovim,* and *Yiddishkeit* in general. Put them on in the car and at bedtime. You'd be surprised at how much kids pick up from simple stories and songs.

E. Hazan

There is an amazing range of kids' books on a variety of topics. *Baruch Learns about Pesach, Baruch Learns about Shabbos,* and *Baruch Learns His Brachos,* are a few good basics ones. There is also a whole slew of *middos* and *hashkfafah* books, such as: *Let's Break Bad Habits* and *The Hidden Artist.*

Also, I learned from *Rebbetzin* Spetner the importance of sharing with your kids when you're excited about something. So, for example, one day I was listening to a song about "*Aleinu lishabeiach*" and it was so uplifting that I kept singing it to myself the whole time. I shared that with my kids, explaining the beautiful meaning of the words. Basically, we need to share any time we're excited about Hashem's Torah and *Mitzvos!*

P.J.

We had a similar experience with our daughter who felt left out at the Shabbos table when I asked the kids questions about the *parasha* of the week. We started asking her "yes" and "no" questions, to which she was able to shake her head with the correct answer. Even though they were very simple questions, such as: "Did Hashem make the whole world?" "Are we allowed to eat non-kosher food?" or even: "Does Hashem love Esti so much?"—the point was that she got to answer, just like her siblings, and felt very important and included.

D.F.

Thank you so much for raising this very important topic! It is a pet peeve of mine that families often act as if a diagnosis automatically creates a total *heter* for special children to be free of *Yiddishkeit*. It really bothers me when I see what looks like a lack of caring about *halacha* and *minhagim* when it comes to special children's *chinuch*. As a parent myself, I understand that not every child could or should be obligated in every *mitzvah*. But we should try as much as possible to have our children keep all that they possibly can, in the best way possible. If a child can speak, they should be taught to say *brachos,* answer *amen*, *daven*, etc. Being disabled is not an excuse for a girl not to dress modestly. Even when it comes to *middos*, why are we so quick to make excuses for them, and not train them to share, wait their turn, be respectful, and stay quiet when necessary? Obviously, when something is not possible, then it's not an option. But, as I write these lines on *Erev Shavuos,* I can't help but point out that all of us, including our special needs children, stood at *Har Sinai* and said *"Na'aseh V'nishmah."* It is the parents' job to be *mechanech* all of our children, according to their nature and abilities. Let us not absolve ourselves from this sacred task, even when (and especially when), the child in question is an extra special *neshama*.

E. Levy

Question for the next issue:

What is the nicest thing that someone ever did for your special child (or for you, relating to your special child)?

Please send us your answers to: neshamalemagazine@gmail.com or text your answers to: 848-299-2908

Let's Get Educated

Vision Therapy

Leah Tawil, SLP

The information in this article is primarily taken from AAPOS (American Association for Pediatric Ophthalmology and Strabismus). Some of the information is based on my own informal research, specific to my daughter's particular diagnosis. Please keep in mind while reading this article, that each individual's diagnosis, and therefore treatment, is unique, and needs to be assessed by an ophthalmologist whom you trust.

What is vision therapy?

Vision therapy, administered by optometrists, is a program consisting of a series of in-office and at-home reinforcement exercises, intended to improve visual skills and abilities. There are three main categories of vision therapy:

1. "Orthoptic vision therapy" – these are eye exercises used by pediatric ophthalmologists and orthoptics to improve binocular function. The exercises are taught in the office and carried out at home.
2. Behavioral/perceptual vision therapy – eye exercises to improve visual processing and visual perception
3. Vision therapy for prevention or correction of myopia (nearsightedness)

Lenses ("training glasses"), prisms, filters, patches, electronic targets, and balance boards are other forms of vision therapy.

Does vision therapy work?

According to AAPOS, orthoptic exercises can be beneficial in the treatment of symptomatic convergence insufficiency (eyes not aligned), however, behavioral vision therapy is considered to be scientifically unproven. As well, there is no evidence that vision therapy delays the progression of, or corrects myopia. There is also no experimental evidence to prove the benefit of "training glasses."

After doing my own informal research by interviewing friends who benefited from vision therapy, and speaking with an unusually open-minded ophthalmologist, I came to the following conclusion: While there may be some benefit from vision therapy for minor issues, for the most part, it is a gamble of money and time. I view it as falling into the category of other alternative medicines, which work for some and don't work for others. (Of course, we tend to hear only about the success stories!) For this reason, vision therapy is generally not covered by insurance.

What is the connection of vision therapy to learning disabilities?

Contrary to common belief, scientific studies have proven that ocular coordination, motility, and visual processing are actually *normal* in children with dyslexia. Hence, scientific evidence *does not* support the use of eye exercises in improving academic performance in children with learning disabilities.

The reason that teachers sometimes recommend vision therapy to a student who has problems with reading or writing, is because he/she is under the common misconception that dyslexia is a problem of letter or word reversals. Reversals of letters and words are normal in early reading and writing development. So, although these problems occur in both normally developing children and in children with learning disabilities, they are not included in the definition of dyslexia. Letter and word reversals have been shown to be a symptom, not a cause, of reading disorders. A language disorder (i.e. auditory processing disorder) has actually been discovered to be the root of most reading disorders, rather than a visual/perceptual issue. So, when children display difficulty reading/decoding, it is due to lack of comprehension, not because of "tracking abnormality."

Should I get my child's eyes checked if he/she is having academic difficulties?

Yes. It is a good idea to rule out any eye or vision disorders, because some children may have a treatable visual problem along with the reading or learning issue. Treatable eye problems include: strabismus ("cross-eye"), amblyopia ("lazy eye"), convergence and/or focusing deficiencies, and refractive errors. Additionally, (if I may add in my own two cents, as a speech-language pathologist:) definitely check hearing as well!

RESOURCE GUIDE - Part I

Helpful resources you may not know about

Compiled by Dinah Wadiche

Being the parent and "case manager" of a special needs child is a daunting job, with copious amounts of information and advice to sort through and large bills to pay. Over the years I'd heard vague references about government programs, grants that fund therapy, etc. The leads pursued usually led to defunct programs, or to programs with specific requirements that the child didn't meet. I knew there had to be some real assistance available for local families, and I was determined to find it.

Together with my sister, Esther Hazan, another devoted, tireless parent of a special needs child, we found a plethora of widely untapped funding to help manage the life of a special needs family. We combed through websites and brochures and did extensive research to create a pool of reliable information. Slowly, a listing of grants and available funding began to take shape.

By sharing our discoveries by word of mouth, thousands of dollars of equipment and assistance have already been granted. We feel driven to share this information, and hope the readers of Neshamale will benefit from this guide.

For information or assistance in applying to the grants or foundations listed, or if you have experience or more information about any of the resources, or to add to the list, please call/text: 848-326-1512. We also have paper copies of application available for many of these programs.

INSURANCE GOVERNMENT PROGRAMS:

1. Incontinence Supplies (through Medicaid)

You can receive diapers, disposable gloves, and disposable diaper pads through Jersey Care. Amounts received vary according to your child's needs.

Two such companies:

1. Aeroflow Urology: 844-276-5588

For ages 3 and up. Your pediatrician's office will need to sign paperwork.

Insurance accepted: Amerigroup, United HealthCare. Call regarding acceptance of other insurance plans.

2. A Medical Supply: 516-300-1414

For ages 4 and up.

Accepts Amerigroup, United HealthCare.
Call regarding acceptance of other insurance plans.

1. PPP Personal Preference Program (throughMedicaid in NJ)

Starting at age 5 (if the child has severe disabilities it may be earlier), this program pays anyone – including a family member – to help with your child. You can hire yourself or your spouse and use the payment for any need, hire an aide, cleaning help, etc. There can be more than one caregiver enrolled at the same time. This government program issues checks that count as income for the recipient.

Payment amount varies according to your child's age and disabilities.

Start applying a few months before the child turns 5, as it takes time from the initial call until starting the program.

Start by calling your insurance to request the program, and they will guide you in getting started.

For more info or help applying, call:

PPP Customer Service: 1844-880-8702
Amerigroup: 1800-600-4441
United Healthcare: 1800-493-4647

- Once on the program, you will need to fill out timesheets to clock hours online. You can request a call-in option if using a landline.
- Tip: make sure your landline is given as the original contact info, and that it is listed with Medicaid as well. It takes time to switch, so do it right when you start, to avoid waiting to be able to clock in hours.
- To switch phone number with NJ Medicaid call:
- NJ Family Care: 1800-701-0710

2. Subsidy (New Jersey)

If you are not eligible for, or do not have Jersey Care, you can be eligible for Subsidy, cheaper insurance premiums through the marketplace.

For more info, call **LRRC: 732-942-9292**

HOSPITAL STAYS:

1. Harps Hope **www.harps-hope.org**

Food and gas vouchers for families with a child in the NICU or a long-term hospital stay. Apply online.

2. Opens Doors Foundation **202-557-2929**

Home assistance program for children currently being treated, or who were recently treated in the hospital – with a minimum seven day stay.

They pay your rent / mortgage for one month in a 12 month period. You can reapply each year.

For children under 21 years old (or under 26 years if they are still a dependent).

You can also be eligible if the child has 30 or more hours of nursing home health care.

Apply thru your hospital social worker. They work with 17 hospitals across the county, including CHOP.

Attention Readers: Many of these programs are only applicable in NJ. Please use this list as a springboard to research similar programs in your community. We'd love for you to share with us any information that may be helpful to our families..

Well-timed Messages

L.M

SWEET SPICES

Introducing "Sweet Spices," our new column about seeing the hashgacha/providence in everyday encounters with our special children. The title is based on the following Torah medresh:

When Yosef's brothers sold him into slavery, the Torah mentions that the caravan in which he traveled down to Mitzrayim carried sweet-smelling spices, as opposed to the foul-smelling cargo usually transported on that route. Rashi points out that this brought comfort and encouragement to Yosef, who understood that Hashem prepared these sweet spices to accompany him on his journey, and to teach him an important lesson: Although it was painful that he had been sold into slavery and sent down to Mitzrayim, it was not random. It was orchestrated by Hashem, down to the very last detail, and Yosef knew that he would not suffer an iota more than was destined for him.

As we journey through life with our special children, we need to remember that Hashem is the One planning this journey, with all of the bumps and jolts we may encounter. Let's try to smell the sweet spices along the way, and be encouraged by the knowledge that nothing is random, and that we are on a journey to greatness!

It had been a hard day. We spent the long draining day in the hospital, taking MRI and CT scans of my two year old princess. Then we waited over an hour for a car service in the rain and biting cold. The first car drove off without finding us, and the second car made me run two blocks to meet it. When we finally arrived at the car, I was greeted with yelling from the nasty looking driver. On the way home, my princess, still disoriented from the anesthesia, vomited all over the car. (I have since learned to ask for a dose of post-anesthesia Zofran before leaving the hospital, and to bring along a Chux disposable pad to use as a huge protective bib).

I had reached the end of my rope. "That's it!" I said to myself, "As soon as I get home, I'm getting into bed. Forget about food (I was actually starved!), forget about the other kids coming home from school, forget about all the work waiting for me at home." I tried calling to ask my husband to please meet me at the door, to help me out of the car with my vomit-covered baby and our millions of bags (courtesy of trach and g-tube life). My phone had 2% battery left and I wasn't getting through. I finally reached him when we were nearly home, but it was not meant to be, as he was unavailable to come home to give me a break.

So there I was, *shlepping* all the bags out of the car, when plop! they landed right in a big puddle on the street. Meanwhile, I was also juggling soiled blankets and my sleepy child, and I still needed to clean the car. It wasn't the prettiest picture, nor was I in the prettiest frame of mind.

When we finally made it up to the 6th floor, I ran to charge my phone, and a message popped up:

From: Rofeh,Doctor <Doctor.Rofeh@hospital.org>
Sent: Someday, Pre-COVID era, 3:23PM
To: Princess's Mom
Subject: Thank You and Happy Holiday

I arrived to the clinic on this cold, rainy morning and was greeted with your beautiful gift. (He was referring to the gifts we had dropped off that morning.)

Thank you so much! I don't know how you find the time and patience to be so warm, caring, and generous to those around you. You are a wonderful mother, a wonderful human being, and an inspiration to us all. Thank you again for your lovely gift, and I hope you have a chance to celebrate the holiday with your family. Please give Princess a hug from me.

Sincerely,
Devoted Rofeh

When I read those words, my exhaustion and hunger faded, and it gave me the extra boost I needed to face my kids and deal with my evening. Although it was the doctor's words, I know that it was really Hashem sending me the *chizuk* I needed just at that moment!

A few days later came the moment of truth, aka scan results.

The results were not unexpected, but not what we would've liked to see. In addition, my daughter was crowned with a new diagnosis, on top of her already colorful, rare complex situation.

My reaction? Did I even have time to process my feelings? I had to push them aside to deal with our upcoming appointments with out-of-

State specialists. Not to mention all the technicalities of the insurance nightmares.

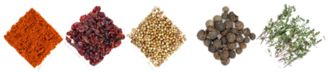
When I found a few minutes to tune into my feelings, I wrote this:

New diagnosis ringing in my ear,
New diagnosis bringing us fear.
What does this mean?
More 'medical machines'?
Will it just bring more hospitalizations,
More medications?
How will we cope?
It's no longer a joke.
Hashem Ya'azor
There is a plan,
Yet, I don't know because I'm only a woman.
Ein od milvoldo, again and again,
Ein od milvado, sing it all day in your brain.
We will daven and daven and storm the heavens
With Hashem's help Princess will get 100% better,
But meanwhile, let's hold on to this dream
While "HELP ME HASHEM!" I'll continue to scream!

Then, two days later, as we were processing it all, Hashem, in his infinite kindness, sent us the *besomim* we so desperately needed. I got a call from a world-renowned organization that has helped us along our roller coaster/medical journey. This time it wasn't medically related—they were calling to let me know that we had won a big prize in their auction!

We were ecstatic! We started dreaming about how we'd spend the money we so desperately needed. I felt so embraced and loved by Hashem, as if He were whispering: "I'm here, I'm with you, carrying you through this tough journey. I'm at your side until you reach the other side in triumph."

It was a real *chizuk* boost, after which we embarked on an unknown road, starting Princess on an investigational drug through compassionate use. Boruch Hashem, it is now two years later, and I can say (after an extended rough and tough period) that this was a turning point in my daughter's life, as ultimately it proved to be a helpful drug for her condition.



A Sister's Perspective

B.S.

When Mrs. Green walks into the classroom, I feel Despair, my little companion, settle on my heart. He is reserved for special situations, such as today's quiz that I did not have a chance to study for. This companion of mine doesn't help me out on these tests—rather, he makes me feel tense and forget the little that I already do know. I much prefer that he would leave, but he doesn't give me much of a choice.

I look witheringly at the paper, hoping the answers would come to me just by gazing at it long enough. But it doesn't work. I feel Despair taking up more and more space in my heart. Despair must not realize how badly I wished to do well in Mrs. Green's *Chumash* class this year. He just sits there and laughs mockingly as I fill in desperate attempts at answers.

Today I will do it! I decide. Today I will go to my teacher and tell her that there is a real reason for my lack of studying. The reason is not a lack of motivation, nor is it empty excuses. I will tell Mrs. Green, and she will look at my test differently.

When the others pass up their papers, I keep mine in the corner of my desk. I go over to Mrs. Green at the end of the lesson, but when I look into her big, caring eyes, I lose my courage. "Mrs. Green?" I stammer as I hold out the paper. Her nod is so encouraging, but I cannot do it. I'm scared I will break. I don't want to cry. "Um, I wasn't able to study. Shabbos was very busy in my house." "I understand," she says.

I wonder what my wonderful, caring teacher really understands. Does she understand that when I said I was busy I meant that I was busy dealing with my sister who was having way too many seizures? Does she realize that I, a meek 12th grader, was the one who accompanied my little warrior in the *Hatzalah* truck? How can she know that this was the Shabbos of my brother's Bar Mitzvah? And on top of this, that I was recovering from strep throat and still not feeling that great.

Mrs. Green, how can you know how badly I wanted to do well in your class this year? It would be quite ironic if you think I lack motivation when I don't fill in how long I studied. How I wish I was able to study for our weekly quizzes!

No, Mrs. Green, I did not tell you all this. There is so much that I wanted to say, but I just couldn't. No one can ever really know what is going on in the lives of others. But I hope, Mrs. Green, that when you said "I understand," you realized there may just be a deeper meaning to the words "I was busy this Shabbos."

Smart & Safe

BACKYARD SUMMER FUN

Fraydel Dickstein

Far out in the Pacific, there was an island that had the most magnificent singing mankind has ever heard. It was so beautiful that whenever any ship would pass, the passengers would be attracted to the gorgeous songs. They would immediately turn their ships to the direction of the singing and try to reach the island. It was actually a suicide mission, as the island was completely ringed with rocks and the ships that dared to go near it would get torn to shreds. The shipping companies were at a loss as to how they could ever ship to any destination nearby that island. They were losing too much money with each failed attempt. They hired a new captain who claimed that he would be able to navigate the route without any problems.

They thought he would ask for special navigation tools or perhaps rock barriers, but all he asked for was an orchestra aboard his boat, a simple request that was immediately granted.

He set sail at once, on what the shipping companies had deemed a suicide mission. As his boat got close to the island, he instructed his orchestra to play loud, beautiful music. On the return trip he once again instructed them to play beautiful music. To everyone's amazement, the ship traveled back and forth safely.

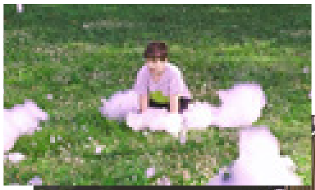
This story makes me think of our Foamo machine, a great example of a time where we made sure our family's orchestra played so loudly and beautifully that we couldn't hear about all the things that we can't do. Yehuda was coming home from camp and I was desperate to do something really fun with the kids. There were two goals I was trying to accomplish: one was that the kids should associate Yehuda's homecoming as something incredibly exciting! I also wanted it to be something Yehuda would enjoy. Going out with Yehuda is a huge challenge, so I was trying to think of something mega to do at home. I hit upon this idea – I would make Yehuda a foam pit, something I knew he loved. I found directions on how to make a homemade foam pit with a wet vac and a garbage can filled with soap. We ordered a wet vac and went shopping for a big swimming pool for it. I took a worn-out towel to function as a sort of mesh and tied it to the garbage can with a string of rubber bands around it. We had the time of our lives! The foam that blew out of our homemade contraption was fluffy and oh, so much fun! Yehuda and his siblings simply could not get enough of it.

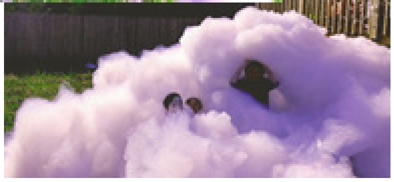
The following Sukkos I was trying to figure out what to do with my family, including Yehuda. I was looked into getting a splash mat, and, although I didn't end up buying it, I have seen many families with special needs children use them. They give hours of fun and can be used on a porch or a lawn.

SplashEZ 3-in-1 Splash Pad, 60" *($18.29 on Amazon)*

I ended up ordering a real foam machine instead. Although not a cheap item, I thought it came out cheaper than a big *Chol haMoed* trip. It was worth every penny, and we have used it many times since. (Beware that the kids can't get enough of it and it may cause rashes!)

Little Tikes FOAMO Foam Machine *($218.00 on Amazon)*





Another great activity, which I did a different *Chol haMoed*, was to borrow a bounce house and blow it up in my dining room. It was such fun! I have a friend who did this nightly. The nice thing about having it indoors is that you don't have to worry about the weather. It may be worth buying one of your own, if it's something you would use more than once or twice a year.

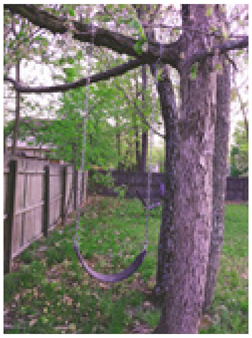
Little Tikes Jump 'n Slide Bouncer *($188.00 on Amazon)*

This one is intended for children ages 3-8, and there are many other options, depending on the size you want.

Often we have no perfect solutions. No, my house will never be perfectly clean, at least for the foreseeable future. But we have other beautiful things to focus on. (My industrious 13 year old, Yehuda, clears all rooms that he currently occupies. Bathrooms need to be clear, so all toothbrushes, toilet paper, and baby wipes land in the hallway. He likes to watch videos in my husband's study, so he transfers the contents of the study into the dining room. I am currently engaged in cleaning out the old files in the filing cabinet so we will have a secure place to put papers.)

My children are really proud of our swing room. We are certainly the only ones on the block who have a room with multiple swings hanging from the ceiling. (See Smart and Safe issue #5 for indoor swing products.)

Indoor swings are amazing, especially for the winter, but they don't take the place of outdoor swings. When we moved to our new house, I started to price swing sets and they were just way out of my league. During my search, I stumbled upon these exciting outdoor swings. I had this great idea of using the trees and, for a few hundred dollars, I now have a beautiful yard. I personally love the rustic look.



TURFEE Heavy Duty Swing Seat *($29.99 on Amazon)*

This swing is standard, but so incredible. I threw it over a strong tree branch and Yehuda loves it. I have a friend who hung this indoors on Ikea suspension hooks and her family enjoyed it as well. It's a simple classic pumping swing that we all know is just so much fun!

I also hung a hammock on my trees, which Yehuda just loves to chill in.

MOSFIATA Camping Hammock *($39.99 on Amazon)*

Did you know that you can have a whole "ropes course" in your backyard for under $100?! This is simply incredible!

Ninja Warrior Obstacle Course for Kids *($79.99 on Amazon)*

I have been intrigued by swings that go on their own stands, as they eliminate the installation phase which is hugely complicated for our unhandy family. It also does not require a tree, which is not always available.

Live Casual Universal 4ft. Or 5ft. Outdoor Swing Stand *($199.00 on Amazon)*

I would assume you can put any kind of swing on this stand. I can even see it fitting in a tiny city yard.

I had always dreamed of making the walls in my house into rock climbing walls. I haven't gotten to it yet, but this looks really fun, practical, and not too costly.

12 Ninja Tree Climbing Holds for Kids Climber for Outdoor Ninja Warrior Obstacle Course *($45.99 on Amazon)*

Some of these more expensive versions can possibly be covered by grants and foundations that sponsor things for children with special needs.

I will end off with a little story: I once walked into a furniture store to buy a couch. The salesman showed me vinyl as a cheaper alternative to leather. I asked him: "Is it really, really strong? Because I have a severely autistic 10 year old." To which he responded: "Well, in that case, nothing will be good." I did not want my kids to hear his defeated lingo, so I looked at him and said: "We just built a beautiful house. The whole house is made with my son in mind, and we will get a couch that is good for him as well."

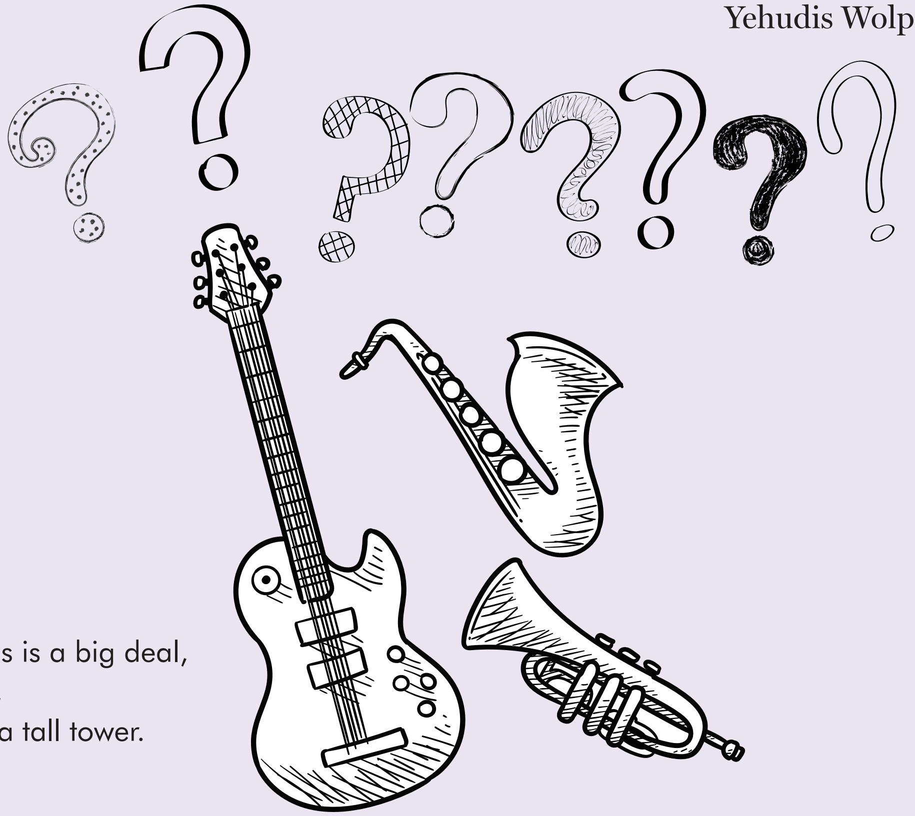
Yes, we try to play our orchestra loudly, and enjoy all we have. (By the way, I finally had the courage to install window shades in my house. Let's hope I will still be happy with my decision next time I write a Smart and Safe article!)

Good luck playing your orchestra loudly—and don't forget to dance to the beautiful music. May we all be *zoche* to dance with all our children and greet *Mashiach* very soon!

(The story about the island was inspired by a lecture from Rabbi Leiby Burnham)

A Bar Mitzvah for Whom?

Yehudis Wolpin



Look and see—
Is this Bar Mitzvah for him,
Or for me?

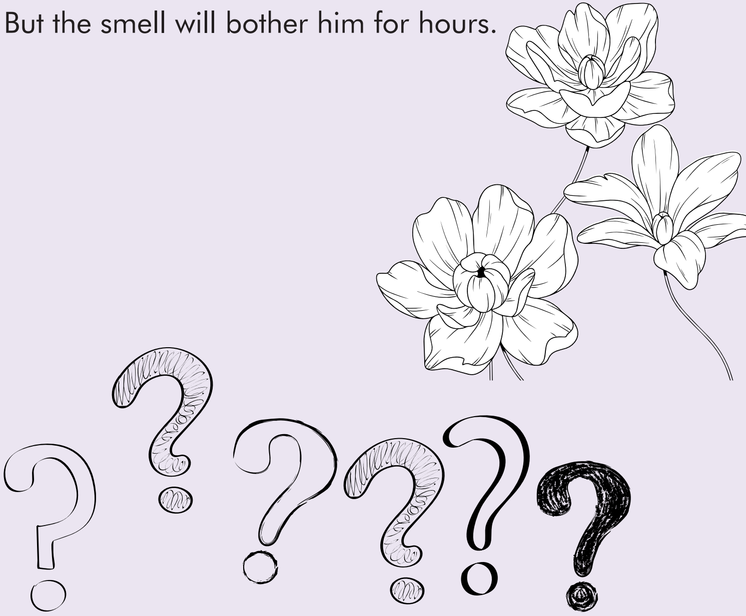
When you want a crowd,
But for him, it's too loud,
Or a five piece band,
Playing music he can't stand,

Look and see—
Is this Bar Mitzvah for him,
Or for me?

You may want a six course meal,
But for him to sit more than five minutes is a big deal,
Or you want a speaker every half hour,
But for him, that's like having to climb a tall tower.

Look and see—
Is this Bar Mitzvah for him,
Or for me?

When you want a photographer,
But for him, that's pure torture,
Or you want lots of fresh flowers,
But the smell will bother him for hours.



Look and see—
Is this Bar Mitzvah for him,
Or for me?

It's his big day, let's not forget,
So why cause him pain, or make him fret?

If you skip the crowd,
        skip the band,
        skip the meal,
        skip the speeches,
        skip the photographer,
        skip the flowers…

Know that you are doing the right thing,
Now you are letting his heart sing.
Without all the trappings, he'll feel all your love,
And Hashem will be smiling too, from above.

GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

Note: All words are in Ashkenasic (Eastern European) pronunciation. (Y) indicates term is Yiddish (A) indicates Aramaic

Ad biyas Go'ayl – Until the arrival of the Redeemer
Aibeshter – The One Above (ie: G-d) (Y)
Alef-Bais – Hebrew alphabet
Aliyah – (lit: to go up) 1) to move to Israel; 2) to be called up for the Torah reading in synagogue
Amen – So be it!
B'meheira v'yameinu – idiom: May it be soon, in our days
Bachur, Bochur – Young man; unmarried Yeshiva student
Baruch Dayan haEmes – Blessed is the truthful Judge (said upon hearing of a death)
Besomim – Sweet spices
Borei Olam – Creator of the World (ie: G-d)
Bracha/Brochos – Blessing/s
Chas v'Shalom – God Forbid! (lit: Mercy and Peace)
Chesed – Acts of kindness
Chizuk – Strength, encouragement
Chol haMoed – Intermediate days of Jewish holidays of Pesach and Succos
Chumash/Chumashim – the Five Books of Moses/(pl)
Daven/davening – Pray, prayer (Y)
Drasha – a talk on Torah
D'var mitzvah – Object used in performing a mitzvah
Dvar Torah – Short Torah lesson
Ein Od Milvado – There is no one but Him (God)
Eretz Yisrael – the Land of Israel
Gebentched – Blessed (Y)
Geulah – Redemption
Guf – Body
Hachnasas Sefer Torah – Celebration for a new Torah scroll
Hadlakas Neiros – Candle lighting
Haftorah – Torah reading taken from a section of the Prophets
HaKadosh Boruch Hu – The Holy One, Blessed Be He (G-d)
Halacha – Jewish law
Hapa'am odeh es Hashem – At this time, I will thank HaShem
Har Sinai – Mount Sinai
Hashem Ya'azor – G-d will help
Hashgacha – Supervision
Hashkafa – Torah outlook
HaTov v'ha'Meitiv – He (G-d) is good and does good
Hatzalah (the organization) – Jewish Emergency Medical Service
Havdalah – Concluding ceremony of Shabbbos
Heilig – Holy (Y)
Hodu L'Hashem – idiom: Praise God!
Koach, Kochos – Strength/s
Kosel – the Western/Wailing Wall in Jerusalem
Leibedig – Enthusiastic (Y)
Maariv – the Evening prayer service
Madreiga – Level
Magid (of Mezritch) – Inspirational story teller (from city of Mezritch)
Mashiach Tzidkeinu – Our righteous Messiah
Mechanech – Educator
Mehudar – Better, more beautiful or exacting standard
Mi k'Amcha Yisroel – "Who is like Your People of Israel?" (Jews are so awesome!)
Middos – Character traits
Minhag/minhagim – Tradition/s
Mitzvah/mitzvos – Torah Commandment/s
Na'aseh v'nishmah – "We will do and we will hear" (Jewish vow of obedience to Torah said at Mt. Sinai)
Nebach (noun/adj) – Unfortunate one/pathetic (Y)
Negel vasser – Ritual hand washing upon arising (lit: nail water) (Y)
Neshama/neshamos – Soul/s
Niftar – Passed away
Parasha – Weekly Torah section
Pasuk – Verse (of Torah)
Peckel – Burden (lit: package) (Y)
Petirah – death
Pshetel – Bar Mitzvah boy's Torah speech (Y)
Rasha –Evil person
Rav – Esteemed rabbi
Refuah, Refuos – healing/s
Retzuos – Straps of Tefillin
Ribono shel Olam – Master of the Universe (G-d)
Ruach haKodesh – Divine inspiration
Schmoozing – Shooting the breeze (Y)
Seudah, Seudos – Festive meal/s
Seudos Hoddah – Meal to publicly give thanks to G-d
Shabbos haGadol – The Shabbos before Pesach
Shechina – the Divine Presence
Shema – Foremost Jewish prayer, declaring the oneness of God
Shiur/Shiurim – Torah lecture/s
Shlaymus – perfection
Shlepp – Drag (usually something heavy) (Y)
Shlita – Blessing for long life (abbreviation), often appended to names of religious leaders
Shomer Shabbos – Shabbos observant
Shul – Synagogue (Y)
Simcha – Joy; joyous occasion
Siyum – Ceremony on completing a section of Torah study
Sofer – Scribe
Sukkos, Succos – Holiday of Tabernacles
Tafkid – Purpose, task
Tamay – Impure
Tefillin – Ritual objects worn by Jewish males during morning prayer
Tefilla, Tefillos – Prayer/s
Torah – Five Books of Moses; inclusive term for body of Jewish observance and life
Tzaddik/tzadikim – Righteous person/s
Tzadekes – Female tzadik
Tzedakah – Charity
Tzitzis – Ritual fringes on specific four-cornered garment worn by Jewish males
Yarmulke – Skullcap worn by Jewish males (Y)
Yeshuah/Yeshuos – Salvation/s
Yiddishkeit – Judiasm (Y)
Yom Tov, Yomim Tovim – Jewish holiday/s
Zechus – Merit (noun)

"Embrace the unique way your child is blooming - even if it's not in the garden you imagined."