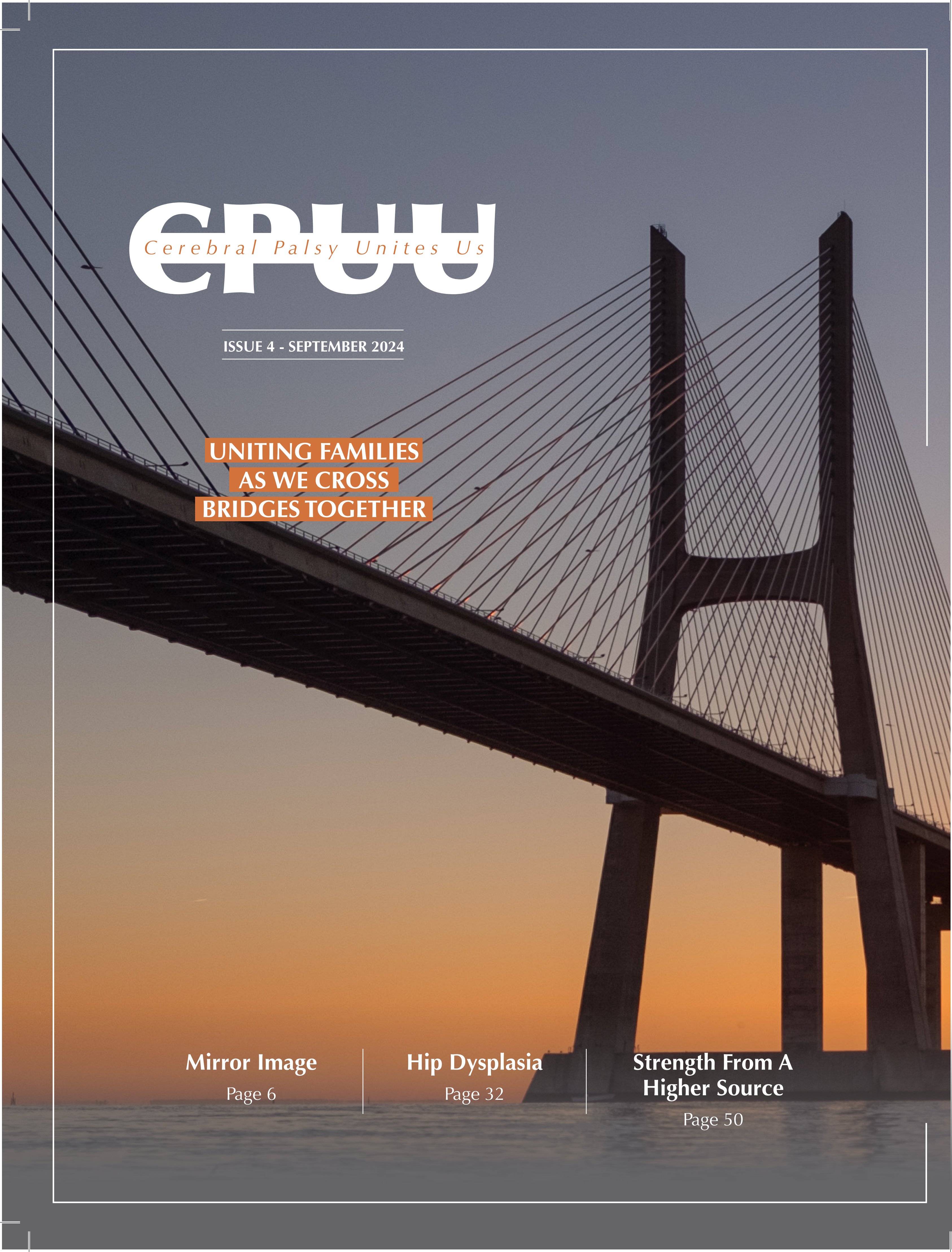

CPUU

Cerebral Palsy Unites Us

ISSUE 4 - SEPTEMBER 2024

UNITING FAMILIES AS WE CROSS BRIDGES TOGETHER

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Note: This magazine contains Divrei Torah.

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SHARING JOURNEYS

EXPERT'S SEAT

SMILES AHEAD

Editorial

Dear CPUU Families & Friends,

Welcome back to the new year! I can't believe we're here again and *Chodesh Tishrei* is coming up soon. We definitely feel it in the air. *Baruch Hashem* we're all so busy, hustling, bustling, shopping, cooking, baking, and what not in preparation for the highlight of the year - the *yamim noraim*!

Here is my favorite *mashal* on the topic of *Chodesh Tishrei*.

It was a wonderful day. Mommy was busy in the kitchen, going from supper to laundry, to the baby, to the phone, when suddenly, in walked Eli!

"It's Eli!" he yelled. Mommy can't believe Eli is home already! I'm sure you all know Eli. He's the Eli that comes home from cheder, on a nice day, and everyone knows he is there. A myriad of cries pierce the air.

"Mommy! I didn't do anything, and Eli kicked me!", came the cry from Boruch. "Mommy!" came the bitter sobs from Dovy, with heated tears trickling down his face. "I built a huge tower, and out of nowhere, Eli came running and just smashed it down to pieces!" "Eli, please don't bother me now", said Esther. "I'm so busy!" Eli did not know where to put himself. He was a jumpy, energetic child, arriving home after a tiring day of sitting in his seat for so many hours. As soon as he entered the house, everything was in turmoil!

Ring...ring... Mommy ran to get the phone. Had she guessed who was calling, she wouldn't have picked it up that fast. It was Eli's rebbi again! "We don't know what to do with him!", came the rebbi's voice. "Eli is just intolerable, Mrs. Spira! There must be some big change in Eli, or else he will have to suffer the consequences! We will not allow this any longer!"

Right then, Totty walked into the house and sent a stern look Eli's way. Eli dashed into his room and slammed the door shut. Suddenly there was a giant screech. He had slammed the door right onto his finger! Totty came running, with Mommy on his heels. Chany dropped what she was doing and ran down the stairs. "Should I call *Hatzalah*?!" she shouted. Eli was crying uncontrollably! His finger was blue and purple and bleeding all over! Totty held his finger, wrapping it in a towel. Mommy went running to get cream and a bandage. Big sister Chany was dialing *Hatzalah*, while Baby Dovy came running with his lolly, hand outstretched to Eli. Shmuly came running with his new set of cars, willing to give them all up to make Eli happy. *Hatzalah* was there within seconds. With a sticker in one hand and candy in the other, they tried to stitch him up and save his finger.

What happened here? In the above story, Mischievous Eli was supposed to suffer consequences because of his be-

Editorial *continued*

havior. Why was he given all those prizes?

(*continued on page 4*)

We're approaching the *Yom Tov* of *Rosh Hashanah*. As we know, there's a full year behind us. As shameful as it is, we must sadly admit that yes, we did do plenty of wrongs. Unfortunately, we did plenty of things that we shouldn't have done. There is a heavy court case ahead of us, and on all sides; there are malachim piling up more and more accusations against us. There are big ones and little ones, purposely done *aveiros* and some mistakenly done *aveiros*, but the numbers are rising and it's becoming fearfully overwhelming. The intensity is unbearable. How will we survive this year with *chalila* so many punishments ahead?

And suddenly there is a loud screech heard all over in *shamayim*!

As it says, when we blow the *shofar*, it literally tips the scale, and the *Ribono Shel Olam* switches over from *kisei din* to *kisei rachamim*! How does this happen? How do we understand this? What's the meaning of all this? The *kol hashofar* is the heartrending cry to the *Ribono Shel Olam*, from the depth of our hearts, coming from all the pain and suffering of *Klal Yisrael*.

It's the painful hip surgery that we went through this year. It's those seizures that didn't let us sleep all those nights. It's those terribly uncomfortable spasms that don't let our *kinderlach* rest. It's the hours of incredible boredom, on lonely Sundays every week. It's those painful therapy sessions, the hospital stays and so much more. It's all in the *zechus* of our dear *neshamalach* with their pure and holy *avoda*, shared hand in hand with us, their chosen parents, that pierces the heavens and brings about a year filled with sweetness, *simchos* and *nachas*!

May we be *zoche* this year to a *shnas geula v'yeshua*. May we hear the piercing, screeching sounds of the *shofar shel Moshiach* that we are so desperately waiting for!

Wishing you all a *ksiva v'chasima tova*, with easy preparations for the *heilege Yom Tov*! ●

The Publishers

Inbox

Hi, I got your email address from Nechumelle Jacobs as I also have cerebral palsy.
Can I please be added to the group to receive the magazine, and can I also get the previous editions?
Also just wondering, would you know if there is a WhatsApp/email chat group for people who have CP?
Thanks very much.

Hi, The CPUU Magazine is a masterpiece!
I see that a lot of work went into it.
I just wanted to share that I'm getting very nice feedback on the article I wrote.
Thank you for letting me be part of this.
H. Gross

Congratulations upon the launch of CPUU Magazine, what a groundbreaking milestone in the world of cerebral palsy. May you continue to be mechazek yiddishe kinderlach and remove the stigma from our G-d given challenges.
I am proud to have encouraged you to forge ahead when this was a mere dream on your part… keep on dreaming and keep on doing!
Warmly,
Sara Sander
Down Syndrome Amongst Us Magazine

What a beautiful and informative edition!!!!
Fraida Flaishman, PhD OTR/L

Hi, thank you so much for sending me the CPUU Magazine.
I would like to thank Dr. Edward A. Hurvitz for his column. I really appreciate the updated, and accurate information on the different perspectives regarding various treatments for hypertonia.
Ruchy Stolzberg

Hi, I really enjoyed reading the CP Perks column written by Breindy Hershkowitz. It was very uplifting, and I actually went and bought her book. It is such a great book, truly inspiring, and I really enjoyed reading it! I would love to get in touch with Breindy, she sounds like an amazing person!
Thank you!
Sarala's mom

Hi, I would like to subscribe to receive the magazine.
I heard about your magazine from Simi Folger, the head of Lev Aim Support. I have a child with CP. His name is Chaim, and he is 3 years old. Yes, please sign me up to the emailing list.
Thank you.
Rochel Markowitz

You're doing unbelievable work!! Chazak ve'amatz!!!
Shaindy Kleinman

This magazine is extremely well done, and I am sure it is a wonderful service to those who need it. Very impressive. I am especially impressed by the balance of personal/emotional material and very practical and helpful material.
Best wishes
Rabbi Akiva Tatz

Please send me digital copies of future issues. CPUU magazine would benefit many families with special needs children with whom I work.
Fradel Klein
Care Manager Supervisor
Comfort Health of Rockland County

We would love to hear from you! Our next issue will be released in March IY"H.
Please specify exactly how you would like your name to appear in print, along with your feedback.
cpuumagazine@gmail.com

Mirror Image

Nechama (Tendler) Waidenbaum

There was once a farmer who had a horse. His horse fell into an empty deserted well, and the farmer was left with the job of burying it.

The farmer decided to be smart. He'd bury his horse and stuff up his well at the same time! So he began...

And he never could have known what he was really doing.

You see, his horse was in truth still very much alive, and he was determined to emerge intact, able, and strong. When each mound of dirt was thrown upon him, the horse shook it off and stepped on top of it, shook it off and stepped higher; using each pile to climb up, up, up - out of the well and into his future.

He used the dirt of his burial as the building blocks for his life.

> I've held onto these meshalim throughout the years as a personal message, a mirror. A mirror into the world of the person I wanted to be, yet at times could only dream of becoming.

There was once a king who turned to his servants with a task. He handed each of them a watering can with instructions to go to the water, fill up their vessel, and water the path that the king had already seeded.

The servants went forward, each of them carrying out their mission with pride, care, and gentle determination. All returned to the king with a smile of success, all but one servant who was holding a jug, overflowing with frustration.

You see, each time the servant tried to do his job, the water spilled out of the cracks of the once whole, yet now broken watering can...

With nothing else to do, he went back to his king, feeling defeated, deficient. Different.

The king, his king, patiently, lovingly heard him out. He listened to his servant's pain and disappointment and confusion and sadness in not being able to serve him like everyone else. With a quiet, strong presence, he listened. He heard everything about his servant's grief in not being able to serve his king the way he wanted to.

Then the king, so patiently and lovingly, turned his servant around and showed him a garden sparkling with the blooming vibrance of the most beautiful, living flowers.

The servant saw that it was precisely the water that leaked through the imperfections of the vessel he was given which enabled the most incredible colors of growth. The servant saw the king's proud, glowing smile- and now he sees, he knows, that every step of his journey was worth it.

There was once a diamond that was rare, valuable, and precious. Sadly, its beauty became a blemish when an ugly, unwelcomed scratch appeared across it.

The king called all of his craftsmen and jewelers to fix it. Yet none of them were able to restore sparkle to the stone.Until finally, thankfully, the king was satisfied with one jeweler's work- and the diamond shone with a brightness that only sadness could have brought.

You see, this jeweler saw the scratch as an opportunity for more light. The jeweler saw a rose where others saw a ruin, and he engraved beauty onto a diamond that forever gleamed with greatness.

I've held onto these *meshalim* throughout the years as a personal message, a mirror. A mirror into the world of the person I wanted to be, yet at times could only dream of becoming.

Growing up with Cerebral Palsy meant living a life of so many contrasting colors. So many varied angles, challenges, realities, and dualities.

I was always a "normal" kid - smart, curious, playful, creative.

I was always a "different" kid - singled out for things that my classmates knew nothing of other than to stare, stare, stare.

I was normal- inquisitive, hardworking, talented.

I was different- confused, lonely, wondering so much, asking so little, and learning too much too soon.

I was normal and social and integrated.

I was different and hurting and isolated and alone, always alone.

I was normal- I helped at home and complained about homework and joined class games at recess.

I was different- I had to go to therapy on midwinter vacation days and had to wear back and leg braces before, during, and after school. I missed out on special things at school too many times to count and lagged during every school activity, just enough to always be last.

I was normal in the child-like desire; I had to always fit in and be well liked by my peers.

I was different in the negative self-perception I held of myself at an age way too young. I was different in the pileup of insecurities that came from too many years of self-judgement.

I was a normal teenager as I navigated those years with intense conversations and *hashkafic* debates.

> The reflection of myself that I see in the mirror today tells me that yes, I am normal and yes, I am different, and yes, that's okay.

I was a different teenager as the intensity and awareness of my limitations and loneliness cast an ever present shadow everywhere.

I was normal - I stressed about midterms and clothing and social scenes like every other high school girl.

I was different - I constantly felt the need to scan the participants of every one of my social interactions, anxiously though silently judging them all to determine if this was a person who would "get it".

I was an active participant in class and an avid reader, writer, and thinker.

I was the sole occupant of my inner world and trusted only my thoughts and my resentments to join me in it.

And sometimes I think back to those years, and the thing that always comes to my mind is sadness.

I was a normal kid who was grappling with a reality that was so full of yearning and searching and wanting. Wanting to just be left alone about braces and therapies and exercise and surgeries and appointments and doctors and therapists and reminders and questions and looks and comments. I searched desperately and ceaselessly for something or someone to help ease the never-ending loneliness. Yearning for validation and understanding of the frustration and anxiety (hidden in layers of angry silence) that trailed through my life and overshadowed it as I continued to be a kid who was so normal and so different and so sad.

And I see myself in the schoolyard, or in the classroom, or in the bunkhouse as that kid with the sad eyes, and my heart is sad along with her.

But then I look again into the mirror and think of the girl I wanted to be, the one I've held onto throughout those years, the one that the child in me could have barely dared to dream of.

And I see her looking straight back at me, with confidence, courage, and strength.

I see her standing gracefully in front of her third-grade classroom, sensitively working to envelop yet one more student's heart in her gentle hands. I see her spreading warmth and love and passion to her high school students and skillfully crafting ideas and messages into lessons that she's worked so hard to live. I see her shop in the grocery store or drive down the highway or wash the dishes or go to PT or do exercise or do so many other very normal, very different things.

I see her there in the mirror. I see me there in the mirror- and I am awed, proud, and oh so grateful for the burial that brought out my building blocks, for the flowers that my tears have watered, and for the sparkling diamonds that are my differences. I realize that I am so very grateful for the grueling journey that brought me here.

With wonder, I think, *"Odcha Hashem ki anafta bi."* Thank you, *Hashem*, for the pain and the challenges.

I see the duality of past and present merging together in a prism of light, beauty, and contentment. The reflection of myself that I see in the mirror today tells me that yes, I am normal and yes, I am different, and yes, that's okay. ●

Auto-correct

Malky Haimoff

Life has a way of autocorrecting as it moves along.

Allow me to elaborate.

Over the course of the last sixteen years that I have been entrusted with caring for my twin girls named Liora and Michal, I have often second-guessed decisions that I made.

For example, I keep going back to their infancy in my mind and telling myself that I should have pierced their ears when they were babies.

You see, I hated wearing earrings as a little girl and I always told my mother that I wouldn't pierce my girls' ears until they asked for it themselves. I wouldn't "torture" them like she "tortured" me. I never forgot the feeling of waking up in the morning and seeing that my mother had once again replaced the delicate gold hoops I had taken out the day before. She said she didn't want the holes to close up, but that was exactly what I wanted. So, I turned my back on my family's tradition of getting little gold posts in my newborn babies' tiny earlobes. My girls were perfect the way they were and would surely begin to ask for earrings themselves once they noticed that their friends were wearing beautiful jewelry. I myself grew up to love jewelry and acquired quite the collection of beautiful, dangling ear ornaments over the years. They would too, I hoped.

However, that day still has not come. My girls never asked for earrings. They have no interest in them at all. Every time I suggest it by showing them a beautiful pair of dangling pearl earrings, they shake their heads and turn away from the glittery treasures I hold in front of them. I have quickly realized the error of my ways. I should have pierced their ears before they could refuse.

Well, wouldn't you know it, fate, and *Hashem* gifted me my two girls at once, taking away any opportunity to learn from my mistake. There was no way for me to schedule the 2nd daughter's piercing appointment even before leaving the hospital. Nope, no do-overs for me, and now my sixteen-year-old girls still refuse to give in to my pleas. I can only hope that their future husbands will give them beautiful earrings as gifts so that they will finally decide to take the plunge and pierce their ears.

So, while not piercing my girls' ears when they were babies may be something I regret for superficial reasons, it's not something that I spend a lot of time thinking about now. I am confident that their bright futures will include beautiful earrings.

My failure at developing my daughters' love for earrings is fun to laugh at, but it's not something I lose sleep over. When it's *bashert*, that decision will auto correct itself.

Deciding on which interventions to use to treat Michal's cerebral palsy is a process that does cause me to lose sleep. It also leads to guilt feelings over options we didn't try.

From the day Michal failed to hit the gross motor milestones that her twin was speeding through, I haven't stopped second guessing my choices in her treatments.

I want to assure you that I am not experiencing a lack of *bitachon* in *Hashem* about how Michal's CP turned out. I know that everything is *bashert*, and everything is in *Hashem's* hands, not the doctors' or therapists' hands. If *Hashem* wanted Michal to be a wheelchair user, she was going to be a wheelchair user, no matter how well the doctors performed during the surgery. If *Hashem* wanted Michal to achieve independence in any area of her life, she would do so despite the doctors' prognosis that she would never be able to do things independently. I believe this with my full heart. This belief fuels my desire to make sure that we are making the right decisions in Michal's care, and that we are indeed pursuing *Hashem's* plan with the correct amount of *hishtadlus*.

However, the fact that some choices don't lead to the expected results throws me for a loop.

For example, before we decided to go ahead with the SDR (selective dorsal rhizotomy) surgery for Michal when she was 3 years old, we did a lot of research on the procedure. We consulted with countless doctors, rebbes, medical organizations, etc. We spoke to the parents of kids who had undergone the surgery. We scheduled extra evaluations to make sure Michal's tone was the "right" kind of tone for positive results in the surgery. With lots of prayers every step of the way, we proceeded with tremendous *emunah* in *Hashem* that the outcome would be positive.

Baruch Hashem it was, and Michal started walking with an adorable walker decorated with ribbons and tulle. She wowed her therapists in rehab, and we thanked *Hashem* every day for the beautiful progress that she was making.

One of the reasons for doing the rhizotomy at such a young age was that it would prevent the orthopedic problems so common in CP. By reducing the spasticity that pulls on growing kids' bones, orthopedic surgery could hopefully be avoided. As difficult as the recovery from the rhizotomy was, the recovery from orthopedic surgery is known to be brutal. No mother wants that for her child.

And yet, that was what we were facing for Michal only five years after the rhizotomy. Her annual x-rays showed that the integrity of her right hip was poor and waiting longer would risk a dislocated hip, lifelong pain and limited mobility. Truthfully, we already knew something had to be done even before the x-rays were read. Despite pursuing so many kinds of therapy, including physical therapy, occupational therapy, aqua therapy, hippotherapy, Medek, Thera suit, adaptive ballet, Botox injections, and so much more, Michal was losing a lot of the walking speed she had gained after her rhizotomy. She was walking shorter distances using a very labored gait. She never complained of pain, but she began to choose to stay put rather than walk even short distances. We once again began making the rounds to consultants and doing research and learned that despite working so hard to avoid it, orthopedic surgery was the next step.

Despite a full schedule of therapies every day, I wondered if I had done enough. Maybe a new therapy being researched in Europe would have prevented the need for this difficult surgery? Maybe a diet higher in protein or calcium would have prevented these issues from developing?

Every doctor will tell you that the outcome of surgery is never guaranteed. There is always a chance that a child won't return to her pre-surgery mobility, or unexpected complications can create new issues. Still, we *daven* and trust in *Hashem* that the surgery will be successful.

When the results of the surgery don't match what we are *davening* for, it is hard to accept that this is indeed *Hashem's* plan. It is beyond painful to watch your child have to endure the disappointment and the life-changing circumstances. That is when the guilt takes over. What did I do wrong? Did we choose the wrong surgeon? Did we bring her home from rehab too soon? Too late? Did we not pursue the correct treatment? Was the timing wrong? Should we have tried the controversial therapy a relative read about years ago and mentioned every time we saw her? Would that have made the difference? Did we not encourage her enough? Did we pressure her too much? Did we not *daven* enough? Did we not have enough *bitachon*? Did we not...

The what-ifs are endless. At the same time, I know that it was *bashert* for us, mother and child, to be exactly where we are right now, exactly how we are right now. It must have always been *Hashem's* plan for Michal to be a wheelchair user. *Baruch Hashem,* she had some wonderful years of adventure chasing her twin sister by running after her. Now, *Baruch Hashem,* she has wonderful wheelchairs that enable her to chase her sister by rolling after her.

We tried to treat Michal's CP with a rhizotomy, with every therapy imaginable, and with orthopedic surgery. We made the decisions based on careful consideration and research. We tried to control the outcome so we wouldn't second guess our decisions. Even with all our efforts, *Hashem* decided it was *bashert*. The results always autocorrected to bring Michal to where she is supposed to be right now.

Because she has never let her disabilities define her abilities, Michal's future is bright and filled with promise, just like Liora's.

There is no autocorrecting that! ●

Michal's
Instantaneous
Curious
Humorous
Amazing
Laughter

Michal Haimoff

My name is Michal, and I am a 16-year-old girl with CP. I have two wheelchairs, and I'm a twin! (It is not as much fun as you would think it is to be a twin, especially when you are the younger one by a mind-boggling two minutes!) My twin doesn't have CP, and we are not identical at all.

I started using my wheelchairs all the time when I was eight years old, after a surgery that didn't have the results that I was hoping for. The doctors said I couldn't wait any longer because my hip was not looking good, and it would cause me to have pain my entire life if they didn't operate. Well, I don't have hip pain now, but I also can't walk with my walker anymore. So that's just as well ... What can I say, *gam zu l'tovah*!

On the topic of wheelchairs, there are good benefits of using one! For example, with my power chair, I can put my feet up in the air whenever I feel like taking a siesta. I can still give hugs and rides to my 5-year-old cousins without breaking my back!

Now for a better introduction to me... I am a Pokeman fan who used to live in Queens and now lives in Marine Park, Brooklyn. Until 8th grade, I attended SINAI @ YCQ, but then I graduated and now attend Kulanu Torah Academy for high school. It is all the way in the Five Towns, so the long bus rides are just "GREAT" for my spasticity... 🙄 I wish I could attend a school in Brooklyn but so far, I haven't been that lucky (that's another story...).

Both of my schools have elevators, which is why I can attend there. But these same elevators break down a lot ... Surprise surprise! Murphy's Law ... Or... What goes up sometimes doesn't want to go back down! Or vice versa!

Just a few Fridays ago, Kulanu's elevator decided to break down while I was upstairs on the third floor. I was getting very nervous as it got closer to dismissal time. Kulanu's usual repairman couldn't get the job done in time. There were four wheelchair users on the third floor, but two of them were able to get down the stairs with the help of their paras. That left two of us who needed to somehow be brought down. The school called the cops and firemen who had a special evacuation stair wheelchair and after transferring to it, it was my turn to be carried down. It was quite nerve-wracking, so I kept my eyes closed the entire time! The people that were already downstairs celebrated with a loud round of cheers when we got to the bottom. The problem was that I still needed my wheelchair for the 45-minute-plus highway ride home on the school bus! My power chair weighs about 300 pounds and the firemen and cops weren't willing to try carrying that down three flights! There were no spare wheelchairs that were supportive enough for a bumpy bus ride home, so it looked like I was going to be spending *Shabbos* in an empty school. Oh no!

Thankfully, someone thought to call *Hatzalah* and explain the situation to them. They arrived and somehow managed to get my wheelchair downstairs without breaking either the chair or their backs! I was so relieved; I couldn't hold back the tears. *Baruch Hashem,* I got home in time for *Shabbos* with quite a story to tell at the *Shabbos* table!

I have only one sibling (twin "A" named Liora), as well as a whole bunch of cousins that I love spending time with. Unfortunately, most of them live in Lakewood so I don't get to spend as much time with them as I would like to. It's hard to visit them in their houses because they all have a million steps to get inside. I also have a fear of heights, so when my uncles lift me up the stairs, I get very anxious. My spasticity makes me tense up more when I am scared. All these things make stairs a true challenge, but once I'm inside, I love playing with my young cousins, talking with my older cousins, and generally catching up with family.

> Hands down, the worst wheelchair issue is how everyone treats you like you're two years old, and when they talk to you, their voices get slower and louder.

When I was in 8th grade, my school and my sister's schools (Sinai and YCQ) were planning their annual 8th grade trip to Washington DC. Since I was able to participate in the school *Shabbaton* a few months before, I didn't think there would be a problem with this trip. However, the organizing school didn't even let my principal pay for the lift coach bus when she offered to so that I could participate. They just decided it would be too much of a hassle. My mother offered to drive me all the way to Washington, DC in our minivan, but that didn't sound like fun. I didn't like being singled out and missing all the fun with my friends on the bus. In the end, my twin went without me, and my classmates went without me and instead of going, I had a special dinner with my aunt and mother at a fancy restaurant! While that was nice, I really had wanted to go on the trip and was quite disappointed. What hurt even more was that at the special senior dinner a week later, everyone was given a "special" present. It was a group photo of the entire grade in Washington! I was not in the picture. I tried hard not to show how grumpy I felt the rest of the dinner. It still hurts remembering that moment. The only consolation I had was that I heard from a few reliable sources that the trip was not so exciting.

I am the only human being in a wheelchair both in my family and in my class, and it has been that way for as long as I can remember. The only place I get to hang with other "wheelies" is in camp! I love my two camps - Camp Simcha Special and Kids of Courage. Needless to say, the summer is my happiest time of the year! Additionally, the occasional *Shabbatons* or *Chanukah* reunion parties are always a fun time to see my friends during the year.

Once, my classmate and I were talking about books that touched our hearts, and she mentioned a book (I don't remember the title) that was about a kid going through school with Cerebral Palsy. I laughed and told her "That's pretty much my life story!" Maybe writing this article is the first step to me writing a book about my own experiences going through school with CP!

I love my brain but at the same time it's also my worst enemy. Sometimes my brain acts like a "Karen" - it acts like I'm the cause of all the trouble, when we both know it's my brain's fault. Especially on days when I'm already frustrated at my life as it is, I don't need anything to make it worse.

Over the years, I have come to feel that CP is like a physical version of ADHD. The brain for a person with ADHD will not be quiet for five seconds. A person with ADHD can continually be moving, while a person with CP can have much spasticity in their muscles. When I'm tired my brain decides to act up and make my muscles move more than ever. Many people do not understand what is happening, and annoyingly tell me to calm down.

Hands down, the worst wheelchair issue is how everyone treats you like you're two years old, and when they talk to you, their voices get slower and louder. To remain polite, you just have to grin and bear it, though I'm still trying to think of the perfect retort to break the awkwardness.

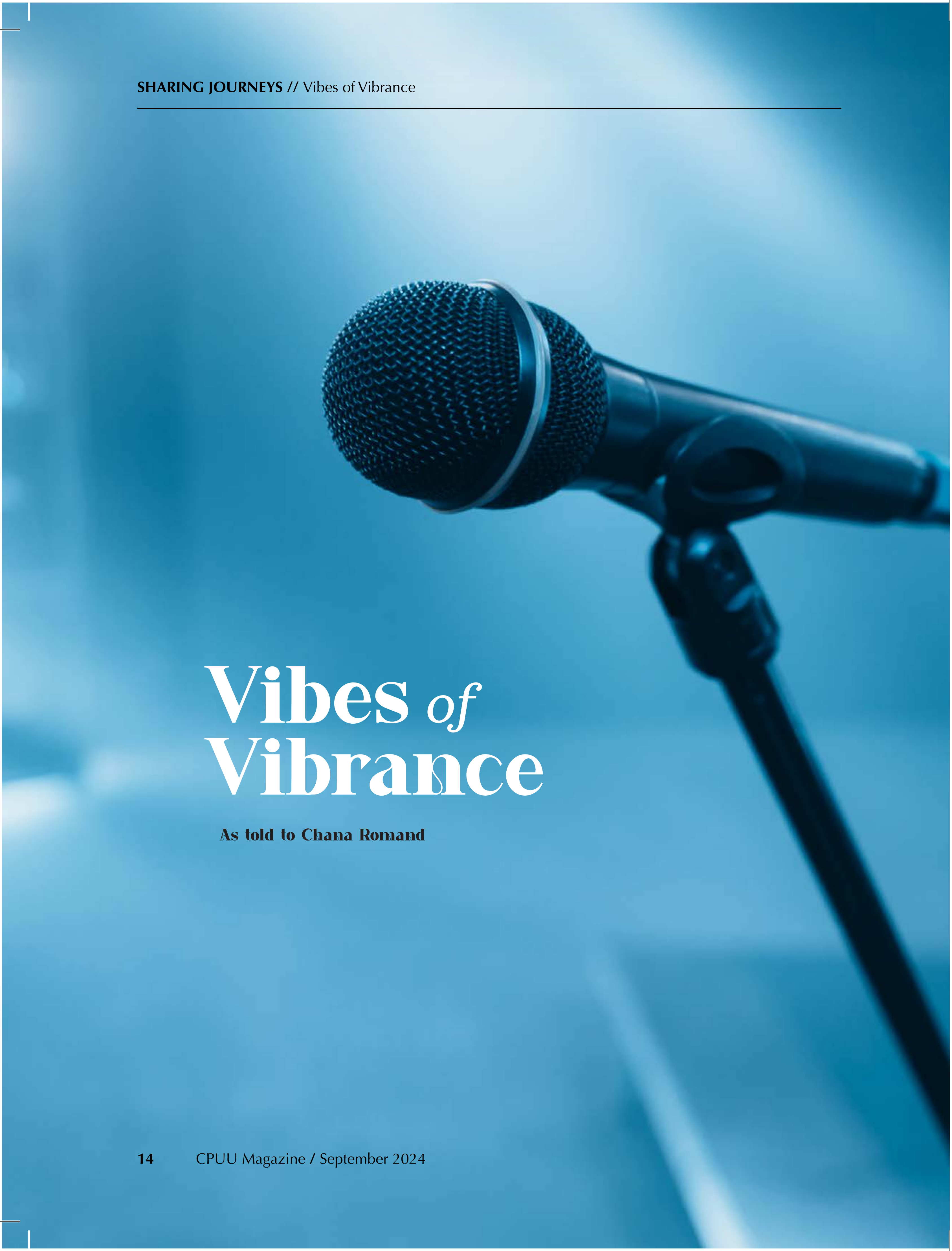
And now for my signature sign-off, a joke:

Q: What do you call a person with cerebral palsy who likes riding on merry-go-rounds?

A: A Fidget Spinner.

LOL!

Do you have any questions for Michal? She would be happy to answer them. Please email her through her mother at haimoffs@gmail.com.



Vibes *of* Vibrance

As told to Chana Romand

Positivity is practically vibrating through the wires. Yenty, an adorable 16-year-old girl with CP, is sweet as sugar and full of life. Her mother's wide smile could be heard clearly in her warm, strong voice. She actually speaks regularly on a Yiddish-language phone line, on which she dispenses her wit, wisdom, and inspiration. Today she is full of rich recollections about Yenty's childhood, spiced with humor and her hearty laugh.

Yenty was born a twin to a healthy sister. She was always a happy girl, smart and beloved, albeit physically delayed. When she played house and dressed up as the mother, she would look in the mirror and ask, "Is there such a thing as a crawling Mommy?" She loved playing with her friends, but could not begin preschool at the same time as her sister because she was not walking yet. She would sit at the window and complain, "Just because I can't walk, I can't go to school?" Eventually, she got accepted to school. She would crawl to get around the classroom and when the girls went outside, her teacher would push her on a Step-2 bike. About twice a week, I would send a small treat with her to boost her social standing amongst the girls. They would crowd around her, "Yenty, yay, Yenty is here!"

Indeed, she was always part of the goings-on at school. When the girls would play ching-chong, she would play along, but with her hands! Once, at a family wedding, a classmate's mother came over to Yenty and I. "You know, I'm so curious, why does our daughters' class have a full day assistant while the other classes have one for only half a day? What's the problem with this class?" She asked. "Oh, there's no problem", I answered breezily, "it's just that there's a handicapped child in the class." The classmate's mother replied, "Really, who?" I responded, "She's standing right here." I pointed to Yenty, who was leaning against me. I watched the woman's eyes pop open in shock and dart to and fro. And a moment later, she was gone!

> **The teacher called me later in shock. "Yenty is so much a part of the class, always with-it and answering questions. I didn't realize she had any disability!"**

In addition to the assistance she was getting at school, Yenty has had therapists working with her since she was very little. One time, I informed her that the therapist wouldn't be coming the next day since she had gone on vacation. "Oh, so she finally got dressed? Every day she comes with her pajamas!" I repeated this comment humorously to the therapist, who made sure to put on a proper skirt the next time she came. She then asked, "Yenty, am I dressed now or am I still in my pajamas?"

When Yenty entered the first grade, she learned to pedal her own bike and was able to get around quite adeptly. She even had a turn to be the class monitor. The teacher put a pile of papers on a chair and Yenty pushed it to the office. Oh, was she one proud helper!

I remember shopping for school supplies before the start of the year. Yenty was excited and begged to come along. The store did not allow strollers inside, so I carried her in and settled her in the aisle. As I was perusing the selection, I suddenly heard, "Move, move!" It took me a minute to realize that the worker's voice was directed at my daughter. I hurried over, only to watch as he brushed past Yenty, causing her to fall over. A pile of notebooks came tumbling after. The man was irate, "I told her to move!" I responded, "But sir, you see, she's a handicapped child." The man replied, "Oh, sorree, soree." I grabbed Yenty in my arms, handed my older daughter the list, and we escaped to the next-door supermarket. They made good business on us as we spent the next hour there, while my daughter finished shopping for school supplies.

In the second grade, the class started off the year with a substitute teacher. When the regular teacher came back, they neglected to tell her about Yenty's disability! The teacher actually didn't realize until she asked the class to bring up their work. Yenty got up and attempted to bring her notebook. The teacher asked, "Is everything alright?" Yenty responded, "Oh, it's fine, it's okay".

The teacher called me later in shock. "Yenty is so much a part of the class, always with-it and answering questions. I didn't realize she had any disability!" On one occasion, the teacher announced that there would be a party the next day. Her friends ran over to her by recess, "Yenty, don't go to therapy tomorrow because without you we can't have the party!"

By third grade, Yenty was walking with the help of crutches. She needed a helper to prevent falls outside of the classroom but inside she was independent and in her element. A substitute teacher once questioned her curiously, “Yenty, do you have a teacher’s edition book near you? How do you know all the answers?!” On another occasion, Yenty was at a wedding. The girls were doing a dance and Yenty was dancing along with her hands. A woman standing nearby asked her, “What are these colorful sticks? Are you playing around?” It took the woman a moment to realize that this was my handicapped daughter! Additionally, when girls would stare at her in the street, she would ask, “Do you want to see my crutches? I’m this way because that is how *Hashem* made me!” This was her attitude and ready answer for any questions about her disability.

People cannot help but be attracted by Yenty’s positivity and zest for life, in spite of her challenges.

In the sixth grade, her class learned the poignant song, “A schoolyard filled with children…”. When *Purim* came around, the class decided to perform this song for their teacher instead of the usual shtick. They had Yenty sing solo for the little boy’s part.

Here Yenty comes on the line and sings in the purest of voices,

“‘I want to walk,’ he whispers
But my legs refuse to go.
I want to hold a pencil,
But my hands just tremble so.

They say I cannot learn much,
But I know it isn’t true.
Mommy, Tatty, someone help me,
Show what I can do.”

Yenty finishes off on this high note. Her voice is indeed a treat for the ears.

The teacher was thrilled. Thereafter, when she wanted to treat the class, she would allow them to perform the song again. Each time she would invite another prominent school personality to watch! Yenty’s golden voice became famous throughout the school. She was even given the star solo at her 8th grade graduation, an emotional tribute to mothers, which is the high point of the performance. The director arranged for the entire first row of graduates to be sitting on stage when graduation began to spare Yenty the ordeal of walking down the aisle.

Yenty doesn’t attend sleepaway camp. A special needs camp is not for her but the regular camp wouldn’t work either. She says, “By the time I get to breakfast, they’ll be up to supper!”

This is hard for Yenty but she is grateful that there is a fantastic day camp program where we live. They have trips twice a week, workshops, and more. She even went to Zoom Flume water park this summer! Her devoted helper convinced her to go and helped her at every step.

Yenty’s friends call her daily from camp to chat, and she sends them a *Shabbos* package every week. Just a few days ago, they called to make sure that she would be coming to see their play. Yenty responded, “Ok, I’ll come, but what should I bring you?”

“Oh, we don’t want any junk, just bring us some of your mother’s marble cake.” Yenty’s friends are good and honest friends! Last year one of them even chose to stay home with her and attend day camp rather than go to sleepaway camp! And no wonder, people cannot help but be attracted by Yenty’s positivity and zest for life, in spite of her challenges. As she writes in her own words:

“Thank You *Hashem*!” I say,
Numerous times each day,
Don’t worry, He will take care,
After all, He is with us everywhere.

When you’re in a dark situation,
Don’t see it as a huge complication,
Your work is to try and start,
To look for the positive part,
Then all will turn out fine,
And your life will sparkle and shine. ●

Yenty’s Mother would love to hear from you! She can be contacted through CPUU Magazine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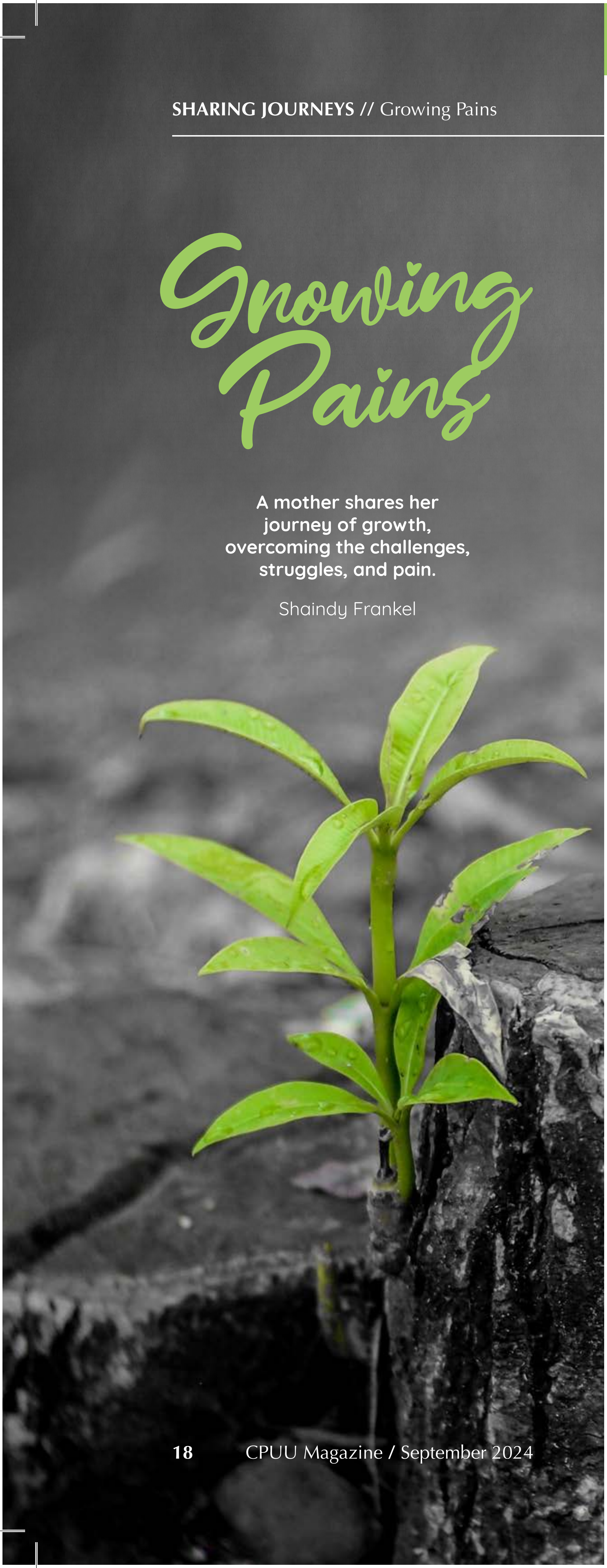
Growing Pains

A mother shares her journey of growth, overcoming the challenges, struggles, and pain.

Shaindy Frankel



I'm grateful for the opportunity to share my story, as it reminds me that I have so much to be thankful for.

People commonly say, "*Hashem* only gives you *nisyonos* that you can handle." I learned, however, that when *Hashem* gives you a challenge, He hands you the tools you need to get through it.

I was a young mother of two, an adorable toddler boy and a little baby girl, when we found out that I was pregnant again. We were overjoyed, yet overwhelmed. I wondered how I would manage with three little ones. As it turned out, that would have been a minor challenge compared to what lay ahead of us.

Rivky was born full term, healthy and delicious. She was a generally happy baby and did as babies tend to do. At one point, we noticed that she had some stiffness. Her hands were always fisted, and her neck was so stiff that it seemed as if it was barely there and did not affect her looks. She had a tiny forehead. Nevertheless, she was a cute, typical newborn and we barely gave this a second thought. At a few months old, she developed a fear of strangers, which kept us extremely busy. She always wanted to be held and only by her parents.

By the time she was four months old, I was convinced something was wrong. She was terribly uncomfortable on her tummy, her hands remained fisted and the stiffness in her limbs did not abate. She wasn't meeting appropriate milestones; such as reaching for toys, turning over or lifting her head off the floor. My pediatrician waved away my concerns flippantly. Prescribing more tummy time, and with instructions to calm down, I was sent home. Not surprisingly, I didn't feel one bit calmer.

At 6 months old, my concerns really went into high alert. Rivky still hadn't reached 3-month milestones, yet my pediatrician was unyielding. Nothing to worry about, he reassured me, she's a late bloomer.

My epiphany came one Friday night. After lighting the candles, I sat down on the couch to relax with a magazine. I chanced upon an article of a mother describing her experiences in dealing with a child with a CP diagnosis. With every word, sentence and paragraph I read, my brain was screaming Rivky! Rivky! Rivky! The symptoms matched up perfectly. My entire *Shabbos* was spent wrapping my head around the fact that my "late bloomer" baby might actually have a real problem. It wasn't a calm *Shabbos* to say the least.

Early Monday morning, I walked into the doctor's office. This time, though, I was determined to bring my point across. The doctor grudgingly agreed to refer us to neurology for an MRI, still claiming that I was a neurotic, overanxious mother.

Appointments are not easy to come by, and I was told there was a 6 months wait. Not willing to sit with it for that long, *Refuah* Helpline came to our aid, and expedited things for us. This would be the first of many times along our journey that they would prove to be invaluable.

I walked into the neurologist's office holding Rivky. The doctor took one look at her and said two words; Cerebral Palsy. As much as this was suspected, I was still shell shocked. I felt alone and utterly lost. The MRI was scheduled to determine the extent of the damage to her brain. The results came back showing lots of damage. They showed that Rivky was quadriplegic spastic tetra paresis in all four limbs. This is the most severe form of cerebral palsy. Rivky had extremely high tone due to a stroke in utero.

It was overwhelming.

Naturally, I began going through the five stages of grief. For those unfamiliar with them, these are denial, anger, bargaining, depression, and acceptance.

My first thought was, "It must be a mistake", When that failed, as it was clearly not a mistaken diagnosis, I reached step two. I started to feel extremely resentful of my situation. "Why is this happening to me? Does *Hashem* make mistakes?"

Then began the months of bargaining. This presents itself as trying to do everything in our power to 'fix' the problem. Running to every specialist that was mentioned, trying each therapy method, and seeking new treatment options to reverse the situation.

At some point it finally hit me. It's here to stay. Honestly, I began to mourn the loss of hopes and broken dreams. Dreams of Rivky's successes and accomplishments. Dreams of my two little girls going to school together, playing hand in hand and being best friends. In my mind, I was that young mother of three adorable children. I knew nothing about special needs kids. It was never something I was drawn to. *Hashem* was clearly sending me a message- I have a different plan for you.

Finally, finally, I began to accept the reality of the situation, finding ways to adapt and move forward. Rivky's disability is now a very valuable and unique part of my identity.

And so began our journey: Doctor's appointments, therapy sessions, evaluations. Hospital visits became routine and tending to Rivky filled up much of our waking moments.

We started with therapy immediately. Rivky had 6 therapists; PTs, OTs, Speech Therapists and Special Educators. Sessions were round the clock, often back-to-back. Life became rather hectic, to say the least. At the time, I left my job, as Rivky's care and my work day proved to be too much of a conflict. While at home, I was able to devote more time and brain space to researching different options that would maximize my child's potential.

At some point it finally hit me. It's here to stay. Honestly, I began to mourn the loss of hopes and broken dreams.

News travels fast and right from the start, the comments from friends and family began. Some people would try to tell us how special we were, but my heart rebelled. I didn't want special, I wanted normal. I tried to only pay attention to the helpful and kind comments, and let the rest go over my head. Interestingly, I noticed a pattern emerging. People would take our lead, in terms of their reactions. When they saw us showing acceptance and calm, they would respond in kind. I also learned that it's okay if there are some people who could not accept it.

Opinions, so many opinions! Whose advice to take? Who to trust? I learned an entirely new lingo: Feldenkrais, Medek, Cranial Sacral, Reflexology, Intense therapy. Anat Baniel, horseback riding, aqua therapy, Botox, chiropractic, osteopathy, SDR.... Seriously, where do I start?

My family was super supportive, pitching in with the other children, as we ran to appointments. I did try to protect our parents by sharing necessary info and keeping them involved, yet not bogging them down with a myriad of details. It goes without saying that I was extremely fortunate that my husband was with me every step of the way, which made everything much more tolerable.

Besides all the regular therapy sessions Rivky was receiving at home, we also took her for private intense physical therapy twice a week, which was located an hour away. Although this was beyond exhausting, we began seeing progress. Rivky gained head control and her neck began to look better. Additionally, we did feeding therapy, due to our hope of avoiding the use of a feeding tube. We give thanks to *Hashem* that Rivky is fully independent when eating today.

One therapist recommended immobilizers, which are soft splints that were worn from wrist to elbow to stretch and loosen Rivky's muscles. We did see some improvement, although this caused lots of staring. I learned to ignore the looks but also got creative and covered the splints with socks that matched her clothing.

Rivky's vision had a shifted focus and her eyes tended to look crossed. Adding more specialists to our roster, we had her fitted with prism glasses.

Needless to say, the expenses were piling up, and our house was beginning to look like a medical facility. We owned a gait trainer, an inversion table, and special chairs, just to name a few of the many pieces of equipment that filled our home...

Yet, despite it all, our life did fall into some sort of a consistent routine.

One *Shabbos* afternoon, I noticed that Rivky looked spaced out and unfocused. I didn't think much of it until it happened again, a few weeks later, this time lasting significantly longer. We rushed to the nearest urgent care to find out that Rivky had experienced a seizure. A little bit of research and one neurology appointment later, we added another diagnosis to our long list, epilepsy. This brought us into a new world of neurologists, orthopedists, allergists, pulmonologists, and ENTs. Rivky was put on medication to stabilize her condition. Despite that, there were still plenty of episodes and ER visits. I learned to deal with them with lots and lots of *tefillos*, and of course, lots of coffee.

Over the next bit of time we tried Botox, which necessitated weekly appointments in the city. They were very tiring, but we were determined to do what we could for Rivky. After several months of these appointments during which she wore large casts on her legs, we realized that it wasn't helping much. We moved on to try something new.

We traveled to Boston for a 3-week program of intense therapy. Rivky did fabulously there and began to move her legs and take steps. At discharge, we got a booklet of instructions for her home therapists to follow. Then Covid hit. Rivky's therapists stopped coming and she, of course, regressed. This was a bitter pill to swallow, and I had to keep reminding myself that it all was meant to be part of our journey, Hashem doesn't make any mistakes, and it's all part of His plan. But boy was it hard.

Covid too, affected our process with home aids. We had made the big decision to bring an aide into our home as Rivky was growing and getting harder to carry around. After going through the grueling governmental red tape, and finally having everything settled into place, covid hit and the aid we were working with left us, never to be heard from again. Eventually, we decided to manage without an aid.

Rivky now left the house in a stroller/wheelchair that attracted many stares and whispers. This never fazed Rivky. She flashed her trademark smile at anyone who laid eyes on her. When she outgrew her stroller, we aimed to transition to a wheelchair that she would be able to maneuver on her own. Yet, after a full year of training at weekly visits to Manhattan, the nurses decided she wasn't ready to maneuver the stroller on her own. This was devastating on so many levels. It was a practical drawback, as we had hoped to develop more independence for Rivky with the stroller. Of course, we felt like the weeks and months of training were in vain.

Rivky attended Eis Laasois, a wonderful school with a wonderful environment. The staff was warm, caring and devoted, and she received lots of therapy. At age 5, we needed to find another school for her. This was a significant challenge as many schools are not wheelchair accessible. In addition, Rivky doesn't speak much and needed a program that was not language based. *Baruch Hashem,* Yad Yisroel accepted Rivky and we haven't looked back since...

> **Rivky really teaches us to appreciate what we have. Her strength and resilience are a reminder never to take anything for granted.**

Sleepaway camp was a new frontier. Some people laid on the guilt for sending such a young child away to camp. *Baruch Hashem,* I had the presence of mind to realize that everyone would gain, and we sent her off with confidence. Rivky truly thrives and loves the amazing experience of camp!

The many respite programs available to our community are invaluable! Rivky goes to after school program, *Bnos*, and *Shabbatons*. All the counselors are dedicated beyond words. There is a constant flow of volunteers who regularly call to take her out. These young teens will never know the indescribable value of what they do for a mother and family of a child with special needs!

Rivky is now an adorable 7-year-old who cannot walk and is in a wheelchair. She wears glasses and has many cognitive and developmental delays. She has extremely limited speech and sometimes uses a device. Despite her challenges she is always smiling, and she's just a joy to those around her. Rivky really teaches us to appreciate what we have. Her strength and resilience are a reminder never to take anything for granted. Rivky faces many obstacles. She struggles to communicate and gets extremely frustrated when we cannot understand what she wants. She can be stubborn and self-directed and wants to be independent even though she can't be. All of this never holds her back from trying. Rivky understands much more than she can express, which makes it difficult.

Rivky is very spiritual and loves *Shabbos* and *Yom Tov*. She especially loves the singing and the seudos. She loves music and dancing. She laughs a lot, and her infectious smile brings happiness to everyone who knows her. She makes people feel so special when she sees them by flashing her signature smile! She has a special connection with her father. She lights up every time she sees him or is told that he will be coming.

I can really see how having a special child in the family has affected her siblings. My children love and cherish Rivky so much. They are so accepting of her. They have a certain sensitivity, kindness and *middos* that you don't see in many young children. Rivky really brings *bracha* and joy into our home. She gives us *nachas* in her own unique way. I feel privileged that I get to do real chessed 24/7. I remember one *Shabbos* when Rivky had a seizure. We called *Hatzalah* because it was not stopping, and when I came into the room, I saw my two other children, who were really young at the time, sitting with *Tehillim* on their laps and *davening*. In the end we did not have to go into the ER, and we knew it was because of the precious, genuine *tefillos* of the children.

The children in the neighborhood all accept Rivky nicely. They try to make her feel good by complimenting her and greeting her with a genuine smile.

Rivky has two younger siblings. As they were born into the situation, it's just natural to them. You can find my 2-year-old going over to Rivky to help her pick up a toy that fell, wipe her chin, or help her get her spoon to her mouth when they see her struggling. It's hard to watch them reach and surpass milestones that she still hasn't mastered, but we learn to appreciate those seemingly small milestones so much more.

Being Rivky's mother has taught me so much. I learned to be more organized and consistent, and I learned to be my child's greatest advocate. The main thing I learned through this journey is to "Let go, and let G-d." We think we can control the outcome of so many things. If I only go for more therapy, she'll do better... If I only go to the top doctor, I'll get the results I want... I quickly learned that *Hashem* has a plan, and though we always try our best to persevere, we are not in control.

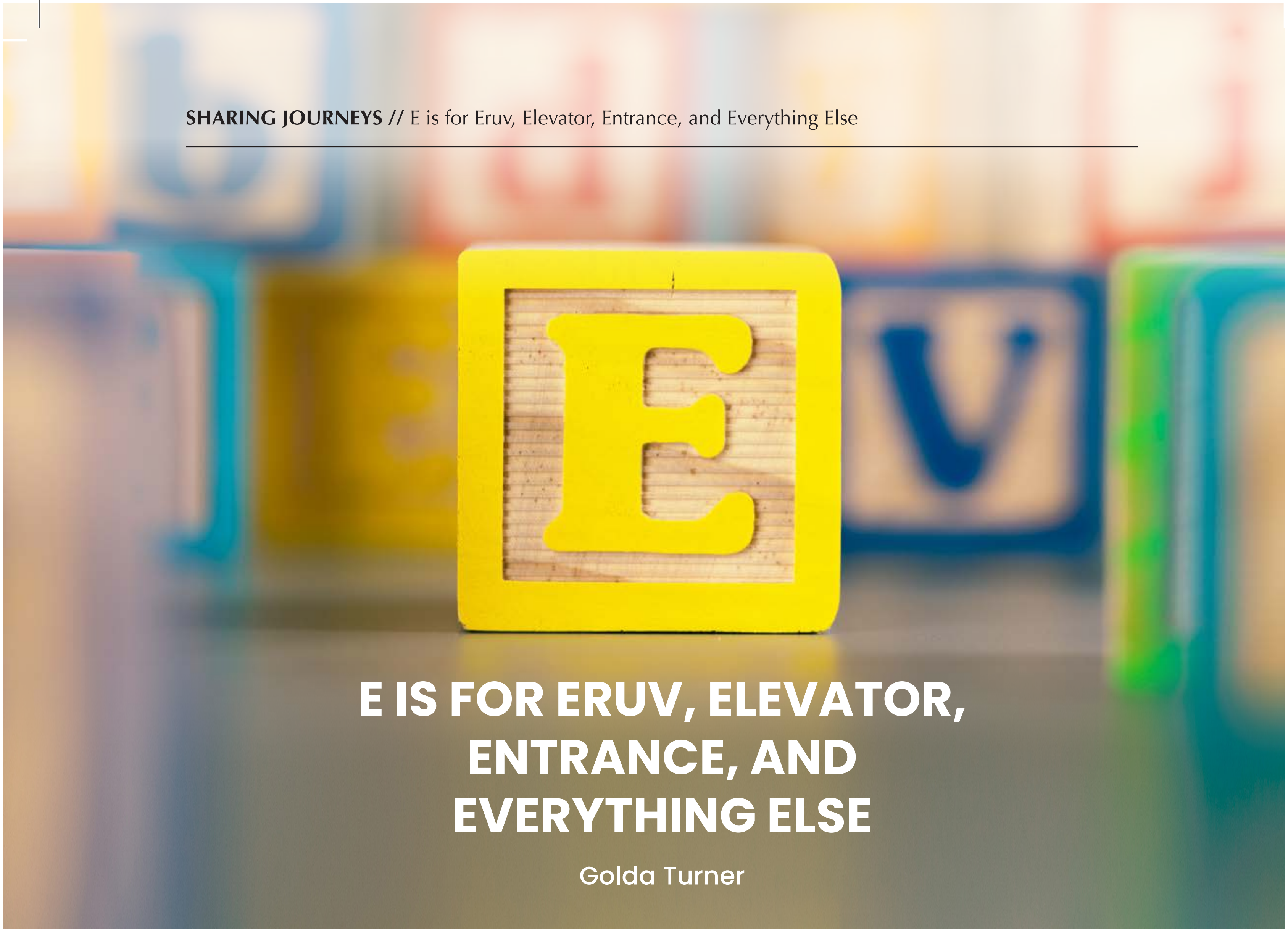
If you think you can do it, you can. And if you think you can't, you're right.

Raising Rivky has taught me all about expectations. Having high expectations just make things difficult. Less expectations means less disappointment. When I got Rivky's diagnosis, I knew that it would be very likely that she wouldn't walk. At one point, one of the therapists promised me that by 4 she would be walking. I remember the disappointment being so great, realizing that the expectation wasn't being met. I learned to be realistic about her situation but still never gave up hope. Miracles do happen. And when we look out for them, we notice that they're actually happening all the time.

I once heard a saying, "If you think you can do it, you can. And if you think you can't, you're right." I find it to be so true. You'd be surprised at how you handle situations when you're given no other choice. You do whatever it takes for your child and your family.

Rivky's determination and spirit continue to inspire all who know her.

She is a living lesson in strength, resilience and *emunah*. ●



E IS FOR ERUV, ELEVATOR, ENTRANCE, AND EVERYTHING ELSE

Golda Turner

Meir Efraim has always been our poster boy, a differently abled hero. Yet even heroes endure ups and downs in the bumpy road of life. And in Efraim's case, being a wheelchair user has undoubtedly given us all quite a bumpy ride.

Efraim starts with the letter E. So do *Eruv*, Elevator, Entrance, and Everything Else. Let's examine these "E" words through Meir Efraim's eyes.

E is for Eruv

Included in the many volumes of *Shas* is *Maseches Eruvin*, which is wholly devoted to one topic: The complicated and relevant halachos of *Eruv*. The entire maseches details how to establish a halachic 'fence' that will transform a public space (*reshus harabim*) into a private one (*reshus hayachid*), enabling one to 'carry' or move objects (or people) from one domain to another.

When Meir Efraim was younger, neighborhood *eruvin* were not nearly as common as today. The only *eruv* in Monsey enclosed a few blocks' radius around the Viznitz Shul. It ended pretty close to our house, leaving us outside the perimeter of the *eruv*.

Meir Efraim became more acutely aware of what he was missing out on when his younger brothers started going to *shul* on *Shabbos*. Three times, every *Shabbos*, he would sit and cry bitterly by the front window. Knowing he was condemned to have many more such disappointments broke my heart. The fact that there were three more disabled adults in our neighborhood, also homebound on *Shabbos*, was even more heartbreaking.

Meir Efraim's disappointment was the catalyst for significant changes in Monsey. My husband contacted the rav who supervised the Viznitz eruv and asked if he would approve an extension of the *eruv* into our street. Within weeks, the expanded *eruv* enabled four people with disabilities to become more involved in the community every *Shabbos*.

With time, the *eruv* expanded to surround greater Monsey, extending for several miles. Eventually, the *eruv* wires were strung high on electric poles and inspected every Friday to ensure their security and *kashrus*. All this is to please a little boy named Meir Efraim, who just wanted to go to shul with his Totty on *Shabbos*!

E is for Elevator

Elevators were designed to transport people and packages from floor to floor, up and down inside buildings. They are also helpful in moving people in wheelchairs from floor to floor, replacing two strong men 'bumping' them up or down step by painful step.

We've had many experiences with elevators, some positive and others not. Some of my greatest frustrations have been with elevators that are supposed to work - but don't.

> **Life in a wheelchair is very bumpy, even on a smooth road. But we learned that even a bumpy road can still get you where you need to go.**

A common reoccurrence was at the local *Minyan* Factory. Sure, the *gabbai* has the key, so wait outside for one minute until someone finds the *gabbai*. Simple? Not really. The *gabbai* is not here now, or he just stepped away, or he forgot the key at home, or he is in the middle of *Shemona Esrei*. And it's either snowing, raining, freezing, or sweltering outside!

Or the family *bar mitzvah* we were invited to, which was held in the *Yeshiva's* basement hall. We were reassured that the principal was also attending and always carried the keys with him. It was no problem - until it was, because the principal came an hour later than we did.

Or my niece's vort that took place in *simcha* hall of a neighborhood shul. The family of the *kallah* booked this particular hall, because someone once saw an elevator in the building. But now, the elevator was being used as a storage closet, with no room for anyone, especially not someone in a wheelchair.

Then a very rich Yid built a magnificent *shul* right next door. Marble floors, expensive wood panels, handcrafted Italian *Aron Kodesh*, luxurious seats, and ADA-compliant with an elevator. It was a dream come true—Meir Efraim could easily go to *Maariv* every night right next door! Until a few months in, the elevator broke, and water leaked into the elevator mechanics; a claim was to be made with the insurance company, and the repairs would be done. Two years later, we are still 'bumping' Meir Efraim down and up the stairs every evening!

The best one yet was at one of our family *simchos*. One of our sons got married in Israel, and the *kallah's* family graciously rented an apartment for us in a building with an elevator.

When we arrived, exhausted from our flight, we found that the elevator was so tiny that the wheelchair could not fit in! We needed to lift Meir Efraim, remove the footplates, and fold the wheelchair. While one person held him in the elevator, someone else would run up or down the stairs to open the wheelchair and help get him out!

E is for Entrance

Entrances and doorways are meant for people to get in and out of a building or room. People in wheelchairs? That's a different story. It tends to get tricky.

It seems that most non-commercial doors are a tad too small to allow the average wheelchair to pass through easily. Then there are the door hinges to account for; they take up some space, too. That typically leaves a very narrow space in the doorway. Without perfect aim, you squish your fingers or bump the door frame. You must be a magician or a contortionist if you need to turn the wheelchair in or out of a narrow hallway.

Or how about entrances with high door sills? Have you ever tried maneuvering a wheelchair over the bump while maneuvering through a tight door frame?

E is for Everything Else

Are you familiar with the large 'PUSH' buttons that are supposed to open automatic doors? Meir Efraim likes to get a hot cappuccino in the pharmacy next door to the health center he goes to. There's a nice wide ramp leading up to the door and a big PUSH button next to the door. I've asked nicely and not so nicely, but that button only worked a handful of times in the past few years. Try holding open a heavy door while maneuvering a wheelchair through. I get plenty of exercise!

Life in a wheelchair is very bumpy, even on a smooth road. But we learned that even a bumpy road can still get you where you need to go. Take along a hefty dose of determination, positive energy, and a good sense of humor! ●

Excerpts with permission from Building Blocks Magazine.

REAL QUESTIONS *REAL ANSWERS*

Shoshana Levin (Zyman), OTR/L

Q My child is very spastic; how can I help improve and encourage his usage of hand movement?
One example of what I would like him to improve on is crossing midline with ease.

A Thank you for your question! As a parent, it can be concerning and frustrating to see your child struggle with movement, especially when it comes to activities of daily living. Cerebral palsy is a neurological disorder that affects muscle tone and movement, and spasticity can make everyday tasks challenging. However, with the right approach and techniques, you can help your child improve and encourage his usage of hand movement. Although each child is different, there are some general guidelines that can help children with spasticity reach functional goals. The most important things to keep in mind are that the goals are functional for the child, and realistic in that we can expect the child to reach the goal.

A. Range of motion- it's always important to maintain passive and active range of motion as much as possible, so that additional stiffness and possible contractures from lack of movement do not occur. Your occupational therapist can tell you how many repetitions per direction of movement to perform. Keeping active, and using the upper extremity functionally is also important for maintaining active range of motion.

B. Vibration can be an important method to change tone short-term, and may improve results in conjunction with other exercises. Targeting specific muscle fibers can inhibit or activate muscles depending on what you want to achieve. Keep in mind that this should only be considered with the approval of a healthcare provider, as some conditions are contraindicated for vibration usage.

C. Assistive devices, such as adaptive utensils or grips, can help reduce fatigue and make eating, dressing, and other daily activities easier.

The most important way to improve hand usage is to encourage your child to use their affected hand for functional tasks as much as possible. This may include feeding, dressing, stabilizing items, and other self-care tasks. Another crucial piece to consider is your child's level of spasticity. When a child is extremely spastic, it may be harder to complete functional activities. Meet your child where they're at and try to give them the "just right" amount of support where they are challenged, but not overwhelmed, and they feel supported. If you see your child, give up when attempting to complete a task, it is likely that the task is too difficult to complete as is. To create the "just right" challenge, the physical nature of the task might need to be changed via environmental adaptations or including a helpful adaptive device. Additionally, increased support from you as the parent may be required.

If your child does not receive consistent OT already, incorporating occupational therapy into your child's routine can be incredibly beneficial in helping him develop fine motor skills and build strength in his hands and arms. An OT can also provide you with customized exercises and strategies to practice at home, tailored to your child's specific needs and abilities.

Good luck!

Shoshana Levin (Zyman), OTR/L ●

Do you have a question for Shoshana?
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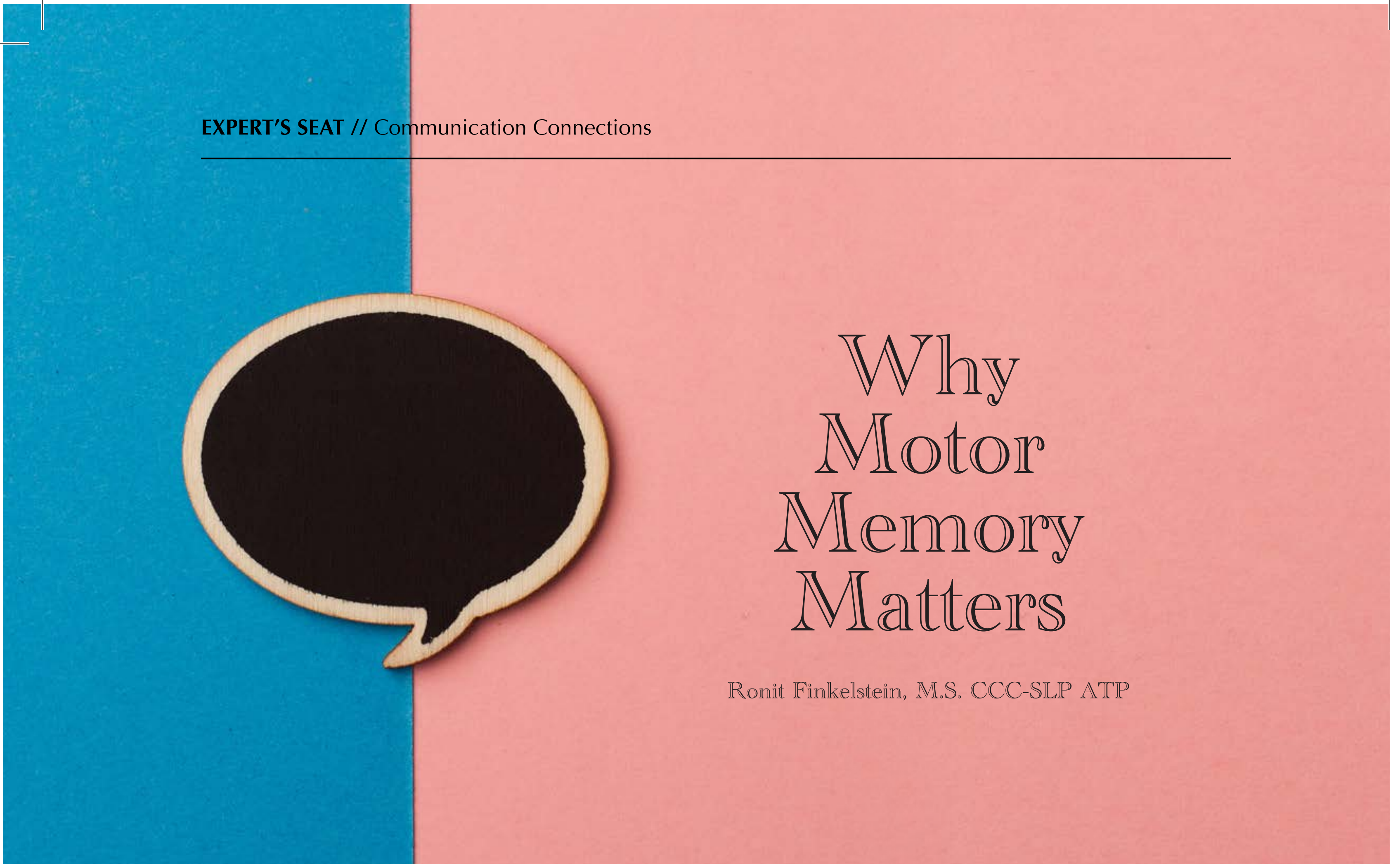
Call: 347-920-0771

"A LITTLE PROGRESS EACH DAY ADDS UP TO BIG RESULTS"



Why Motor Memory Matters

Ronit Finkelstein, M.S. CCC-SLP ATP

Summer is here and with that comes a change of pace. Things are slower and more relaxed. You might be sitting down to read a book you had put aside a few weeks back, or possibly you are going on nice long walks. Perhaps you decided to catch up on your texts and emails. If you chose the final option, I'm sure you spent a relaxing few seconds or minute or hours. You took out your phone or computer, typed a few things without really thinking about them, pressed send and moved on with your day. What if I told you that in order for you to send a text you need to use a keyboard set up in a different layout or language? Would that still be relaxing? Would you be sending as many texts? Would you continue to write long messages? The answer to these questions will lead us to an important concept called motor memory.

Motor memory is when an action has been done the same way so many times that it becomes automatic for your muscles, and you no longer need to think about it consciously. For many of us, sitting, standing, walking or driving is automatic and can be performed while doing other things. However, when there is a change, even a slight change, we suddenly need to focus on that activity. That action can become stressful and require a lot of energy. Picture for a moment that you are driving through the country roads. You feel relaxed, you are talking to your passengers, and enjoying the scenery. A few minutes later, a storm rolls in, and you can no longer see anything in front of you. You will probably be hunched forward trying desperately to see out of your front window while your wipers futilely attempt to clear your windshield. Most likely you will tell your passengers to be quiet so you can concentrate. An action that moments ago was automatic now needs to be conscious and controlled.

How does this relate to AAC, you may ask? Just like we do not enjoy activities that require extra thought and focus, individuals that are using AAC do not either. If they need to search for a word in a different place on each page, the chance of them using that word or even attempting to build a sentence with that word decreases tenfold. While it is important to include motor memory and motor planning in all AAC, there is one company specifically which feels so strongly about it that they have built all their vocabularies/apps on motor memory and motor planning.

If you recall from the last article, I mentioned a company called PRC (Prentke Romich Company). They offer Words for Life, Essence, Unity, and Lamp Word for

Life (Language Acquisition through Motor Planning). Their products are based on the premise that every word should have a motor plan that does not change.

> Motor memory is when an action has been done the same way so many times that it becomes automatic for your muscles, and you no longer need to think about it consciously.

When you select an icon, the page opens up and the verb form of that icon is in the exact same place on every page. To make it a bit clearer, the main verb will always be in the third column, 3rd row down on its respective page. This enables the user to go straight to the verb location on each page without needing to scan every icon or look at the whole page, thus helping communication become more automatic and fluent. Another company, Tobii Dynavox, also created a vocabulary based on motor planning called TD Snap Motor 30 or 66. This vocabulary ensures that each word only appears once within the vocabulary set with a distinct motor plan to access it.

While the above vocabularies rely on motor planning, there are also major differences in their set up. PRC vocabularies are set up according to word families, which would result in the picture of an apple leading you to a page including related verbs, adjectives and other topic folders. When you access the apple icon, it leads you to the category of eating, with the verb eat, and related verbs including chew, bite, taste, feed, and grow. For the adjective hungry, the category name will be food with access to all the food categories (topic folders). Depending on which vocabulary set you have chosen (One-hit, transition, or full) other grammatical forms of the word will also be available, such as hungrier and hungriest. Each page in the full vocabulary set for that word will give the user access to related verbs, nouns, adjectives, and grammatical forms (various tenses, plural, etc.).

While both PRC vocabularies and TD Snap Motor have core words on the front/home page; PRC vocabularies are word families-based while TD Snap motor is set up as a category-based vocabulary. For example, if I wanted to say eat in TD Snap Motor, I would need to go to the actions folder and find the word eat, among the other action words. Tapping on eat would bring me back to the home page. If I wanted to go to the fruits page, I would need to first tap on the food and drink folder and then on the fruits folder. For the word hungry, I would tap on the descriptions folder on the home page, then the feelings folder, and then on hungry.

Some people find the PRC set up easier while others find category-based vocabularies easier. To further illustrate the differences between the two pathways, let's look at the word dog. On TD Snap you would tap on the animal folder on the home page and then on dog. On LAMP (PRC), you would first need to determine the related category for dog, which is come, then go to pets, and then dog. When using other vocabulary sets which are not motor memory based, the word dog can be found under multiple categories/page sets, including pets, farm animals or games.

JUST FOR FUN

Before we wrap up, I am including two "keyboards" to further illustrate the concept of motor memory and automaticity. Choose a sentence such as "My favorite flavor ice cream is chocolate". Now try to type it out using both keyboards.

Qwerty keyboard:

Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M , .

Dvorak keyboard:

, . P Y F G C R L
A O E U I D H T N S
Q J K X B M W V Z

How was that experience? Did it take you the same amount of time? Would you have wanted to keep typing sentences on the Dvorak keyboard? Most likely, it took you at least twice as long to type out the sentence using the second keyboard, and you may even feel that if you ever needed to use that keyboard again it would be too soon. Thank goodness for motor memory and automaticity! ●

MOVING INTO ADULTHOOD

Edward A. Hurvitz, MD

Cerebral palsy (CP) is the most common lifespan physical disability. “Lifespan” means that it starts early in childhood and affects the person’s life course through transition to adulthood and adult aging transitions. Although CP is defined as an injury or malformation in the brain, it affects every part of the body and every aspect of life. CP has always been thought of as a pediatric condition. This was especially true in health care, where adults with Cerebral Palsy were either directed to continue their care in the pediatric settings or were basically abandoned. Pediatric providers don’t really like dealing with adults, and adult providers were not comfortable with CP. Fortunately, the past decade has seen a growth in adult CP specialty care. There has been a significant increase in research related to adults to try to improve understanding about the unique issues associated with growing up with CP.

The average lifespan of individuals with CP has been increasing. People with CP who are able to walk have almost the same life expectancy as people who do not have CP. Those who cannot walk include the group with severe disability which can be associated with multiple medical problems but improved medical care and feeding techniques like gastrostomy tube feedings have increased life expectancy in this group as well. This means that there are significantly more adults with CP than children, which is a whole new way of thinking about Cerebral Palsy.

Older adolescents approaching adulthood go through many transitions. Their educational and social environments become less defined (moving away from the school system they have known for their whole life) and they often must start making more independent decisions about finances, living situation and health care. People with lifespan disabilities face extra challenges. They often have not been given the same development opportunities that other children may have received (being class president, leading retreats, and regular socializing) which leads to decreased ‘self-efficacy” (the belief in your own capacity to do what is needed to accomplish goals). There is often decreased ‘mastery motivation’ (the motivation to act independently.) This can be further complicated by reliance on parents for activities of daily life (ADL) and mobility. Young adults who are more physically independent are still held back by their lack of experience. Cognitive factors may play a role, even people with CP who are not cognitively impaired may have increased difficulties with executive functions such as organization, time management, and prioritization. While many people struggle with these things, people with Cerebral Palsy may have extra difficulties relating to the brain injury or malformation. It is critical for parents to give adolescents every opportunity to learn independence and develop their strengths so that their confidence and self-efficacy grows. There should be increased focus on improving executive functions and practice making increasingly important decisions. They should have access to the many digital programs that assist with organization and schedule planning. For those who need physical help, it is important to give them experience in managing caregivers, including a solid understanding of how to set realistic expectations of care providers and how to schedule life around caregiver availability.

Young adults with Cerebral Palsy generally have lower rates of employment, marriage and independent living than their peers. However, it is important to treat each person as an individual. For example, CP is not a barrier to marriage and to raising children. Depending on physical challenges, there may be some accommodations required for caring for children, such as adjusting access to changing tables and cribs and using slings to hold the baby while walking with a walker or wheeling a wheelchair. These accommodations are available with some exploration by researching them. The most important thing to think about is that adults with CP often have more daily fatigue than people without CP. This must be accommodated into the very demanding job of raising young children. There are special considerations related to pregnancy and cerebral palsy, including the changes in balance that may occur with changes in the body which may increase fall risk in someone who did not have the best balance in the first place. Women need to work closely with their OB-GYN on other issues. It should be noted that mothers with CP do not automatically needs a C-Section. This should be fully discussed with the women's physician.

There are many professionals and executives who have CP who have successfully navigated higher education and entry into the workplace environment. Employment with a disability can be a challenge, for many reasons including access, daily fatigue, and 'ableism,' bias against people with disabilities. Vocational counselors, often available through state services, can be helpful in setting up the work environment or in finding appropriate opportunities. Employers need to understand that there is great value to having people with disabilities in their work setting, as they have much to add to the milieu from their life experiences. As robotics and artificial intelligence applications grow, the workplace will become increasingly friendly for people with Cerebral Palsy, even if there are significant physical limitations. Voice activated computer access, improved modes of personal transportation (such as self-driving wheelchairs) and robotic assistants that can compensate for impaired hand function will create many new opportunities. For young adults with greater cognitive challenges, meaningful programming including supervised work is important for their personal growth and self-esteem. Transportation can be a barrier to employment as well as other important life activities. People with CP who are unable to drive will need an environment with excellent public transportation or with specialty transportation for people with disabilities. Hopefully, the growth of autonomous cars will increase access, currently, autonomous cars must have a qualified driver behind the wheel. It will take some time to get to a point where non-drivers can safely use these vehicles.

Health care is a particularly important and challenging aspect of life transition. Young adults generally move from a highly supported multidisciplinary clinic to a patchwork of care. Primary care physicians often have limited knowledge about the health care needs of people with disabilities such as CP, and often lack the time to give them the attention they need during appointments. Specialists will have similar issues. Physiatrists, practitioners of Physical Medicine and Rehabilitation have taken the lead in opening clinics for adults with CP. These clinics are helpful in addressing rehabilitation needs such as spastic tone and specialized equipment, but are not well set up for general preventive care. Clinics that provide everything needed are few and far between. New innovations provide opportunities for improving care access and quality for adults with disabilities. The rise in video clinic appointments provides easy access to a specialist who is knowledgeable and interested in adults with CP, even if they live a significant distance away. Care providers have greater access to information with the growth in research in the past several years combined with the ability to access it quickly and efficiently using artificial intelligence platforms.

> **THERE ARE SIGNIFICANTLY MORE ADULTS WITH CP THAN CHILDREN, WHICH IS A WHOLE NEW WAY OF THINKING ABOUT CEREBRAL PALSY.**

Preventive care requires special attention for adults with cerebral palsy. Accessibility can be a major problem, especially for some of the tests women need as they age. Some basic preventive care tests do not work correctly in cerebral palsy. One of the major ones is looking at the patient's Body Mass Index (BMI) which is related to weight and height and predicts risk of heart disease. People with cerebral palsy have less muscle and bone, so they can have extra fat in their body and have a normal weight and BMI and still be at risk. Blood pressures may be difficult to measure when there is spasticity. Treadmill tests are not suitable for many people with CP. Fortunately, stress tests can be done chemically now without having to run or cycle.

Monitoring cardiac health has particular importance for adults with CP, as they are generally less physically fit, have less physical activity and more sedentary activity. Their muscles tend to have more fat replacement at a younger age than their peers. All of these things increase cardiac risk, and people with CP have been shown to be at greater risk for hypertension, coronary heart disease, heart attack and stroke. These problems likely contribute to other chronic diseases such as kidney and lung disease which are also seen at higher rates in CP. Physical activity and proper nutrition are the best treatment for these problems. It is important to work with children with CP on patterns of physical activity, including involvement in adaptive sports when available. Adaptive sports have seen significant growth recently with increased attention given to the Paralympics (Olympics for people with disabilities), creating physical activity role models. In some situations, working with the school to help adapt activities in gym and at recess can be helpful. There are many organized adaptive sport activities such as the Miracle League for baseball. Some gyms have specialized devices like recumbent steppers that are more accessible than treadmills and ellipticals. At the very least, it is important to break up sedentary activity by doing more movement during the day.

> **WE DON'T KNOW MUCH ABOUT AGING INTO THE GERIATRIC TIME OF LIFE WITH CP, BUT BY MEETING THE NEEDS THAT COME UP EARLIER IN LIFE, WE CAN HOLD OUT HOPE FOR MORE GRACEFUL AGING.**

Pain is the most prominent complaint of adults with CP. Studies show that 75-90% of adults with CP will have pain complaints, and many will have chronic pain. This pain may be due to poorly formed joints, history of fractures, and/or poor body mechanics. Many physicians have difficulty determining the cause and nature of the pain due to the complexity of the person with CP, but accurate diagnosis is critical for correct treatment. Physical therapy and exercise are generally the first line of treatment, followed by all of the other methods of treating people with pain. Unfortunately, too many people with CP are given narcotics for their pain, which are often addictive and the wrong treatment. There is much work going on to study pain in CP which will hopefully improve care in the years to come.

Several factors contribute to pain. Fractures are very common, this is especially true with aging in both men and women, and is related to poor formation of bones in childhood. Medications for osteoporosis are helpful. Research is needed to know if these medications should be given even before the first fracture. Increased fall risk plays a role in the high rate of fractures. Mental health issues such as depression, anxiety and psychiatric conditions are more common, yet it is not clear why this is true. It may relate to the early injury or malformation of the brain complicated by life situations. Sleep disturbances, such as obstructive sleep apnea, are common. These things can all contribute to pain, and pain can influence mental health and sleep. It is critical that the person with CP and their health care provider work together to break this cycle.

Adults with Cerebral Palsy can stay healthy and active as they age. However, many are at risk of early functional loss. Several of the factors noted above, including poor fitness, pain, fatigue, mental health issues, and chronic diseases undoubtedly play a role. Adults who walk will have a deterioration of their mobility much earlier than their peers without CP. For those with bilateral CP (affecting the whole body), it may occur in their 30's, while those with hemiplegic (mostly one side) CP may find this occurring in their 50's. This is often referred to as "early aging." (There is another term, post-impairment syndrome, which is misleading and should not be used.) Since the various problems discussed so far tend to happen more often and earlier in adults with CP, it is not incorrect to say that the effects of aging occurred to them earlier than expected. However, it is important to remember that early intervention with physical activity, good nutrition, better sleep, and treatment of chronic problems will be key to maintaining health function.

While the transition to young adulthood and middle age is complex for people with CP, there is a growing knowledge base about the relevant issues that can empower the individual to work more effectively within society, their social circle, and with the health care system. Peer interactions with others with CP who have been successful could be very helpful. It is important to consider ways to increase independence and self-efficacy in childhood to improve chances for success as an adult. Teaching critical skills such as regular physical activity, self-advocacy, and methods to overcome deficits in executive functions are essential for maximizing quality of life. Technology has much promise for helping people with CP and disabilities overcome barriers such as transportation needs and organizational challenges. We don't know much about aging into the geriatric time of life with CP, but by meeting the needs that come up earlier in life, we can hold out hope for more graceful aging. ●

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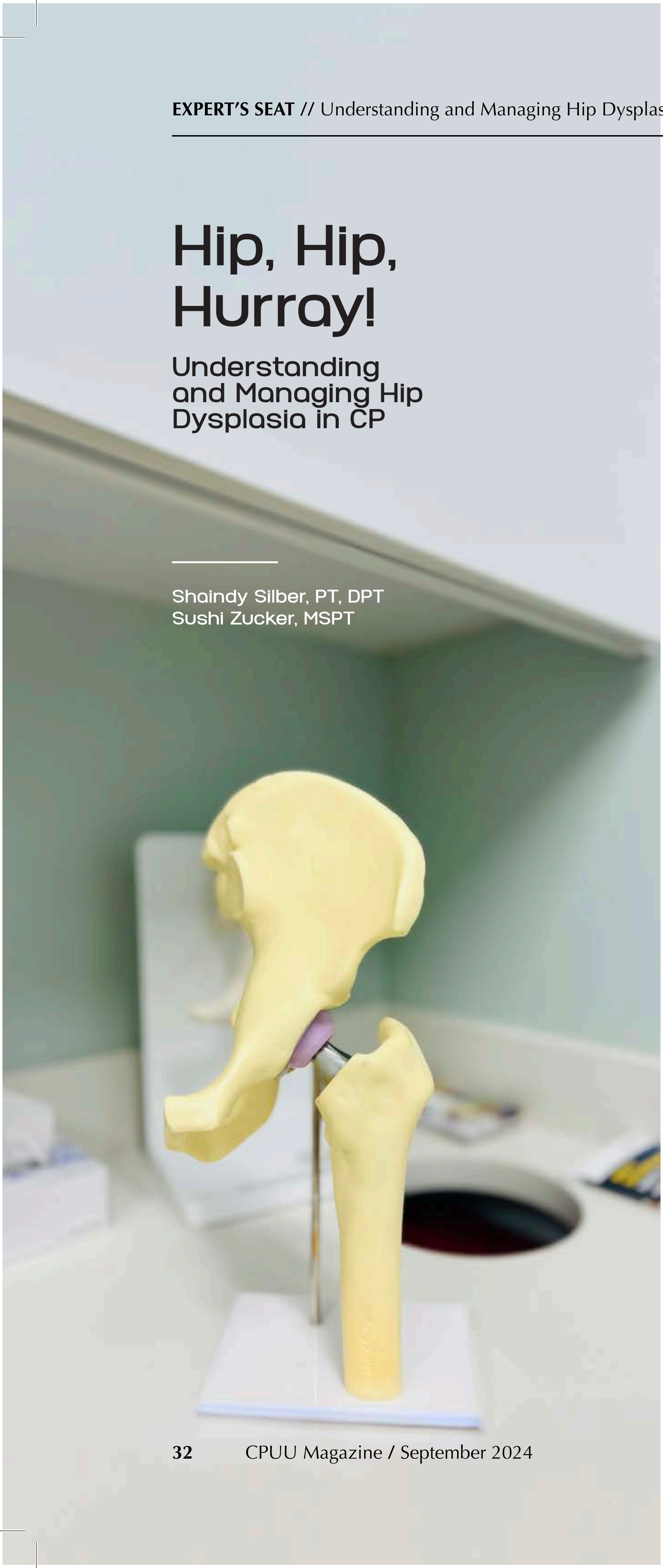

Hip, Hip, Hurray!

Understanding and Managing Hip Dysplasia in CP

Shaindy Silber, PT, DPT
Sushi Zucker, MSPT

We've all heard the terms hip dysplasia, hip dislocation, hip subluxation. It sounds scary and overwhelming, so let's take a deep dive into what they mean and even more importantly how can we monitor it and prevent it? Let's first take a peek at the picture below to familiarize us with some terms that we will be referring to throughout this column:

Image A

The key point to note is how the ball-shaped femoral head (top of the thigh bone) fits into the well-formed acetabulum (the socket on the side of the pelvis), creating a stable ball-and-socket joint. In a normal hip, the femoral head is correctly positioned within the acetabulum (Image A). In a subluxed hip, the femoral head is not properly aligned within the socket, while in a dislocated hip, the femoral head is completely out of the socket. The image below (Image B) illustrates the different positions of the hip in normal, subluxed, and dislocated conditions.

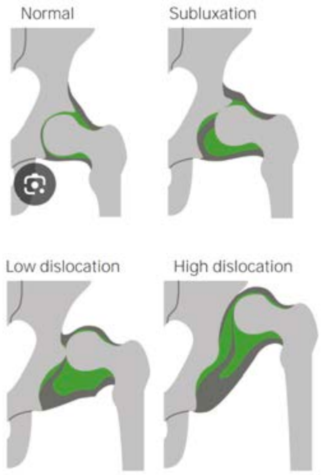

Image B

Hip dysplasia is a significant concern for children with cerebral palsy (CP). Abnormal development of the hip joint can lead to long term complications including pain, arthritis, decreased range of motion, decreased function and decreased quality of life. Nutrition, hormones and medications also affect bone growth. For example, many children with CP s are on steroid medications which can impact bone density. It is suggested that a lack of weight bearing combined with hip muscle weakness cause deformities of the top of the femur, leading to hip displacement. (Ward et al., 2006; Soo, et al., 2006)

Early detection and intervention are crucial to mitigate these risks. In children with CP, it is important to note that hip status is normal at birth, and the displacement of the hip occurs as a child grows. (this article does not address Developmental Hip Dysplasia or Congenital Hip Dysplasia which are different in that the hip is not normal at birth). Hip dysplasia is prevalent, affecting approximately one-third of all children with CP. Their underlying neuromuscular condition causes muscle imbalances and altered bone development, resulting in dysplasia. The risk of hip displacement increases significantly with age and higher GMFCS levels. GMFCS is the Gross Motor Function Classification System, and is a crucial term to understanding the classifications of CP. (If you are not yet familiar with what GMFCS level is or what level your child is please see the chart on page 36.) The risk of developing hip dysplasia increases to up to 90% with GMFCS level five. The peak occurrence of severe displacement is often observed between ages 5 and 6.

> Abnormal development of the hip joint can lead to long term complications including pain, arthritis, decreased range of motion, decreased function and decreased quality of life.

So now that we know what hip dysplasia is, how do we know when the hip is at risk?

Your orthopedist will begin monitoring your child by initiating a Hip Surveillance Program. This includes a physical exam, evaluating the range of motion at the hip, assessing any pain and x-rays to look at your child's hip and its alignment. These x-rays should be started no later than 2 years of age, preferably earlier. Your orthopedist will know how often your child needs x-rays based on their GMFCS Level. Based on that image your doctor will measure the percentage (known as the Reimers Migration Percentage- MP) of the femoral head that lies outside of the acetabulum. This is an important term to remember as we will be referring to it frequently throughout this article. Additionally, understanding it will aid in discussions with your child's orthopedist and therapist. There are other ways to help monitor the progression of hip dysplasia such as via the "Hip Screen App," which allows you to upload the child's x-ray to the app and guides the user through the measurements. It is a great resource for parents and/or therapists.

Once a Migration Percentage (MP) is assigned, what does the number actually mean?

Hips are classified as subluxed (partially out of the joint) with a MP >33% and dislocated (fully out of place) with a MP >40%.

The MP can, and often will, progress as the child ages, indicating a worsening of hip dysplasia. Understandably, hip dysplasia advances the most during the years of rapid growth where the bones are growing and forming. Research has shown that the peak of when hips reach a MP of 30-33% (level of subluxation) occurs between 3 to 5 years of age but can happen earlier. The peak of when dislocation occurs MP >50% (severe displacement), is at 5 to 6 years of age. Our goal is to keep MP <33% until 5, when the most rapid growing occurs. If we can achieve this, then the risk of developing hip dysplasia greatly decreases.

It is important to know that a child's GMFCS level is directly related to how much the migration percentage is likely to increase each year (how far out of place the femur is moving). GMFCS Level I typically advances 0.2% per year, while those classified as for GMFCS V Level can advance at a rate of 12% per year. We can therefore understand the importance of making sure to be on a monitoring schedule. Proper monitoring of the hip allows for timely intervention to prevent hip dislocation (Pruszczyński et al., 2016).

What can we do to prevent hip dysplasia from occurring and progressing?

Since children with CP are most at risk of hip migration during the years of rapid growth, proper intervention in these early years is crucial (Gmelig 2018).

The most promising intervention is actually the simplest. Participating in postural management has the most impact on hip dysplasia. Postural management consists of standing alone or in a stander in a specific alignment to help guide the hip into the socket. One study indicated that 43% of participants who engaged in a standing protocol were able to decrease or maintain their MP below the level of a subluxation, while 53% of participants who did not perform postural management actually developed a progression of MP past the subluxation level (Graham et al., 2008). The studies reviewed consistently showed a greater impact of postural management versus other interventions. For example, a literature review on the use of Botox injections paired with a SWASH brace (brace for the hips) reveals that this helps decrease MP by only 1.4% per year. Another review regarding the use of Spinal Dorsal Rhizotomy, a surgery where the nerves innervating some of the thigh muscles are cut, suggests that it has neither a positive nor negative effect on hip displacement when assessed at least 5 years later (Miller et al., 2023). It does, however, have the potential to interfere with motor function.

Therefore, participating in a standing program is crucial in managing hip dysplasia in children with cerebral palsy. How is standing so effective?

Standing and receiving pressure via muscle activation and weight bearing is necessary for healthy bone development, as it stimulates bone growth and development and is therefore; critical for maintaining hip stability. Research has shown that early and regular standing can significantly reduce the risk of hip migration and maintain hip joint health.

Does any type of standing work?

Standing in a position of abduction (legs positioned out to the side) at a 15–30-degree angle of each leg directs the weight bearing forces into the acetabulum on an angle. As the acetabulum, the head and shaft of the femur accept the forces through them, the bone responds and begins to develop the rounded cup shape that forms a stable hip joint (Martinsson et al., 2021). In a large study of GMFCS IV and V one group stood in 30° to 60° total leg abduction (legs positioned out to the side) for 10 hours/week, while the other groups stood in less abduction of 0° to 20° for the same amount of time. The group that stood in more abduction reduced their MP by 7%, while the group that stood in less abduction actually showed an increase in their MP! This underscores that just standing isn't enough. Standing must be in a sufficiently abducted position (the leg is out to the side 30° to 60°, or 15o-30o each side) for at least 60 minutes per day.

When children stand in standers (either prone or supine), they should be in proper orthotics, often an AFO. This AFO protects the ligaments in a child's foot and ankle and blocks excessive movement and protects the knee and ankle joints. When a person stands in an abducted position, the foot and ankle shift to accommodate the floor, but the AFO blocks this accommodation. It is therefore, crucial for your PT to maintain the alignment from hip to foot with a foot wedge placed under the inner side of the foot, if the stander does not have this feature built in (Yang 2013).

How long does a child need to stand each day to see improvement?

Standing Programs should be a minimum of 5 days per week and can be started as early as 9 months old for children who are not yet pulling to stand at furniture at that time. How long is necessary each day depends on the goal:

Goal	Recommended Time
Spasticity Management	30 to 45 min/day
Improve Range of Motion	45-60 min/ day
Hip Stability	60 min/ day
Bone Mineral Density	60 to 90 min/day

(Paleg et al., 2013)

If your child is currently walking in an assistive device or even independently, one may mistakenly believe that a standing program would not be necessary; after all they are already weight bearing in an upright position. However, we can see based on the above chart that duration spent in aligned standing is of significant importance. Both time and posture are necessary ingredients of a standing program. A child who walks without being in alignment, such as with bent hips and knees, scissoring their legs or walking on their toes, or simply not yet spending enough time standing or walking, will still need a standing program in alignment to prevent hip migration.

Surgical Management

If conservative measures fail to prevent or manage hip displacement, surgical intervention may be necessary. These surgeries range from preventive measures, like soft tissue releases and guided growth, to reconstructive procedures, such as femoral osteotomies (cutting and realigning the thigh bone and/or pelvis) and salvage surgeries, like femoral head resection or hip arthroplasty. Preventive Surgeries are indicated when MP is greater than 40% or there is a greater than 10% increase in MP, while reconstructive surgeries are indicated when MP is greater than 50%, there is evidence of subluxation or early dislocation, or if the femoral head shows signs of degeneration (Shore et al., 2012).

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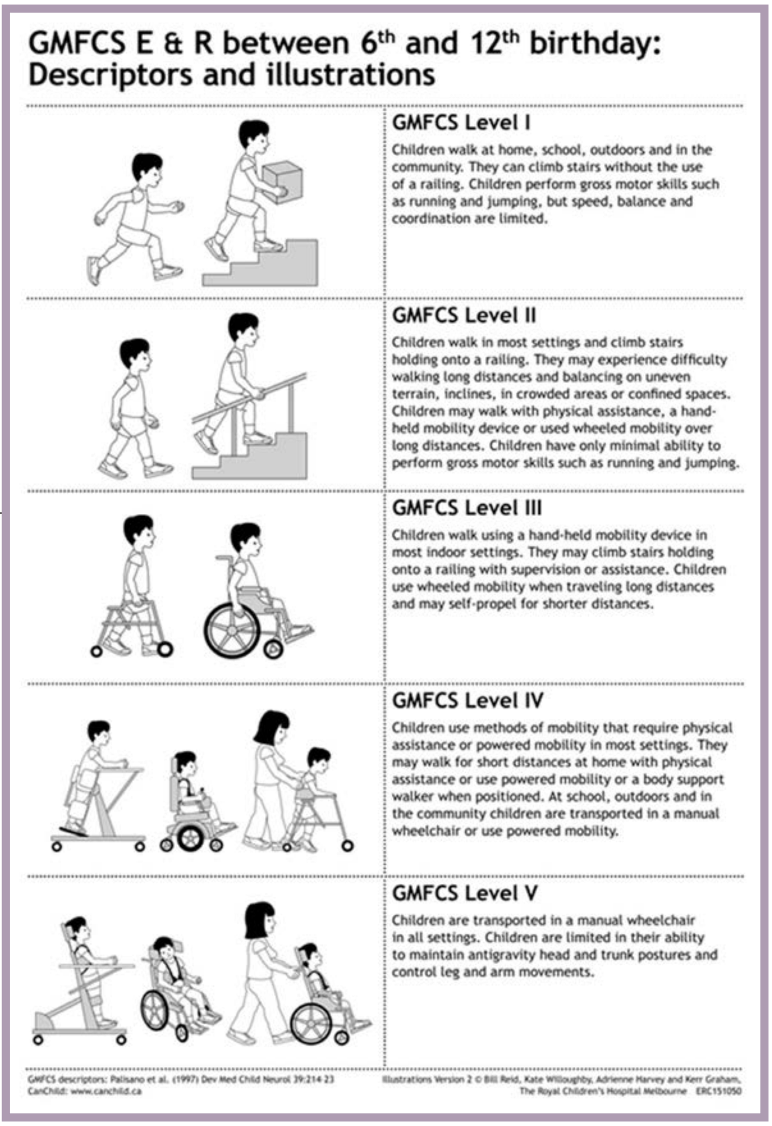
Although surgery can be an intimidating prospect, if the hip has reached a certain point, they may be the only way to decrease pain, improve quality of life and prevent further progression. For further detail and understanding of hip surgeries please speak to your provider team (Palen et al., 2016).

What Are the Most Important Points to Take Away from This?

Let's remember that hip dysplasia is common. It occurs in approximately 1/3 of all children with CP, and the risk is directly related to GMFCS Level. There are frequently no symptoms! Peak occurrence is young at 3-5 years of age, meaning the monitoring and standing must begin in EI. Start the conversation, both with your therapist for bracing and implementation of a standing program, and with your doctors for early x-rays and monitoring. Hip Surveillance is crucial! Let's remember that the goal is to maintain an MP less than 33% by age 5, with the first x-ray at 2 years old and then regularly scheduled exams based on the hip status GMFCS level until age 8 or skeletal maturity. Let's remember that this is a team approach! Standing 60 min/day, 5-7 days per week, at appropriate ranges of abduction has been shown to maintain/decrease hip migration, and standing can start as early as 9 months old for children who are unable to pull to stand by that age. Advocate for standers if your child is not already in a consistent standing program. Let's do what we can to prevent hip dislocations, subsequent surgeries, and improve quality of life together! ●



GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERC151050

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Q & A With Dr. Berkowitz

Dr. Dovid Berkowitz, Psy. D

Question 1: As we put much time and investment into our special child, how can we ensure not to put an emotional toll on our other children?

At the end of the day, your special child really does need more of your time and effort for many different reasons. Therefore, it is very important that you take time on a regular basis to make one-on-one time for your other children as well. Not just for special events and occasions; it's important to do this during random times too. You do not need to set aside a significant amount of time for this, even short amounts are beneficial. This lets them know that you prioritize them as well as all of your children. There are many opportunities for connection with your children within the regular running of the day that you can take advantage of. Some sporadic opportunities include runs to the store, afternoon walks, reading a book, baking or cooking. Some scheduled opportunities can include homework time, bedtime and mealtime.

Question 2: With a diagnosis of CP, there's always more therapies, newer technologies and updated advanced treatments that keep on coming up to help our special child. How can we feel calm and at ease and not carry around the burden that we are not doing enough?

There will always be new and trendy treatments that claim to help or sometimes even heal. While we understand the impulse to run after every new treatment that carries with it some glimmer of hope, you must proceed with caution and only put yourself and your child through ordeals that reviews and research show yield meaningful results. Of course, from a *ruchniyus* perspective, one must always remember that *Hashem* will send our child what they need regardless of how much we run after. Every person based on their particular situation, and strengths must stay within the realm of normal for you. Chasing after every possible lead will only direct you to running yourself ragged. If it will take everything out of you, and there is only a slight possibility of seeing positive results, it might not be considered *hishtadlus* for you. Consulting with someone as to when it is proper to go into a particular treatment plan can take a load off your shoulders and the guilt feelings of not doing enough out of your heart. Obviously, this is easier said than done, but keeping things in perspective will take some of the stress off of your shoulders.

> **Everything we do is hishtadlus; our efforts do not yield results. Chasing after every possible lead will only lead to you running yourself ragged.**

Question 3: As an adult with CP, how can I be at peace with myself despite all the stares, comments and suggestions received by onlookers, strangers, family and friends that make my already heavy burden impossible to carry?

My best advice to dealing with ignorant, or at times tactless, people, is to simply own it. You have a lifelong condition, so coming to terms with it is most important. If someone asks you what's wrong with your arm, why you limp, or why you can't do something, you will be able to say "I have CP", with confidence. If they have follow up questions or seem interested in your condition, just tell them about it. The first time you do this, it might be hard and weird or feel uncomfortable, but the more you own this piece of you, the more you will be ready and prepared to handle these uncomfortable situations.

Question 4: How do I take care of myself as a parent? How do I balance giving support and not compromising their independence?

If your child has CP, your instinct may be to do everything for them. At times, it can seem much simpler and faster to do it yourself. The truth is that, the goal needs to be for them to learn to do everything possible for themselves. If there is something that they can't do on their own, either look for equipment that can assist them in becoming more independent, or do it with them. There are many good occupational therapists who are very skilled at finding tools and tricks for them.

Question 5: How involved should a child be in their own decisions regarding their medical and future needs etc.?

Depending on the age of the child, they may not have the cognitive ability or life experience to make their own decision. But at the very least we should welcome and encourage their input and let them know that we will always consider their viewpoint. They should know that even if their parents did not select their choice, they have shown that they fully considered it and may have even altered their own decision because of them.

Question 6: How do I balance protecting my child from danger and concerns that I have, due to her disabilities, while still allowing her to grow and branch out to be as independent as possible?

Children need to experience life in order to become well-balanced adults. So, while I would not recommend doing anything that is objectively dangerous for any child, try and weigh if the particular experience you are considering is reasonable and safe. If it does pose some risks, there may be something that you can do to mitigate the risk, so it becomes a safe situation. ●

Dr. Berkowitz is a licensed psychologist practicing for over 18 years. He sees teens, adults and couples in his private practice in Nanuet, NY. He can be contacted at 845.354.1547, drdberkowitz@gmail.com

How Can I Help Myself Help My Child?

Rosetta DiTomasso, PT

As parents and caregivers, you already know that lifting, carrying and transferring your children can often be quite a challenge. The questions to ask ourselves are, 1.**“Why is it important to think twice before beginning to lift, carry or transfer your child?”** and 2.**“How can we do it better?”**

The answer to the first question, **“Why is it important to think twice before beginning to lift, carry or transfer your child?”** is quite simply that if you hurt yourself while attempting to carry or transfer your child, you will be harming your child by being unable to help them. Stop and consider, how can I get closer to the child? Where am I starting from, and where am I going to? Can I use squatting and lunging to move the child? Can I change the height of the surfaces involved in the transfer, so they are more equal, so that it will be easier for me? Can I stabilize the child's feet /legs and allow them take some of the weight of the child? Can I position the child on my body in such a way that I am not straining any part of my body? Can I first align my pelvis/ribs using my core muscles to protect my back before lifting and while carrying my child?

The answer to the second question, **“How can we do it better?”** lies in the mechanics of how we move our body to assist our child. There are some key points of body mechanics to consider each time you move your child. Body Mechanics refers to the way in which you move your body when lifting, how you bend and lift, how close you are to the child, and how you position yourself and the child and the environment before you start to move. In general, the closer your body is to the child's body, the shorter the lever arm will be (physics), which will decrease the torque on your body and reduce the force you need. So, what does that mean? Basically, if there is a lot of space between you and the child, you will need more force/strength and power to lift and move your child. A better way to lift is to bend your knees, come down to the child's level, and approach them by positioning yourself diagonally to them. Next, bring your arms around the child, preferably at their pelvis, and then move with your legs in reverse squatting and lunging to move the child. More specifically, let's take **the example of moving a larger child from a wheelchair to a bed or bath seat.** Bring the wheelchair diagonally to the bed at a 45-degree angle. Bring the child forward in the chair so only their buttocks are touching the seat and their thighs are mostly off the chair. If the child can bear any weight at all in their feet, be sure to position them so you can use their weight bearing to assist you. Place the child's feet flat on the ground and position them hip-width apart. Bend your knees and hips and keep your back as straight as you can. Then reach behind and under the child's pelvis with your hands and use your knees to block their knees from buckling. Next, stand the child up (even if just partially), and turn them so their pelvis hits the bed. By starting diagonally, and with your knees/hips bent, you will use the big muscles of your legs. This will help to avoid torquing or pulling on your back or using the smaller muscles of your arms

to lift. Avoiding using these muscles will ensure that you do not sprain your back or hurt your wrists. If your child is completely unable to bear any weight on their feet or legs, you can use a transfer board to make the transfer easier. This is a piece of wood made specifically for transfers. First, remove one side or arm of the wheelchair and slide the board partially under one thigh or buttock and the rest of the board rests on the bed. Then you would use the same technique I described above for moving the child but would move in small increments laterally until the child is off the chair and onto the bed. Next, remove the board.

Yes, both these techniques might take a few seconds or minutes more than just trying to lift the child, but they will prevent you from injuring yourself. **If you could work on only one thing with your child,** I would advise working on trying to get them to put some weight into their legs and practice partial standing, even if only for a few seconds. It will completely change the amount of effort required of you each time the child needs to be moved. Encourage your child to help you when coming to stand. Always position their feet flat on the ground and straight forward, and try to use shoes or non-skid socks or a non-skid rug under them so they can help support themselves, even if a little. Also, always block their knees with your knees.

Also, use equipment when you can, such as the transfer board or a bath chair or a raised toilet seat, so you are not bending over or bending down as much.

Let's examine **carrying a child.** Make sure to place your child laterally along one side of your body with one of their legs bent and one straightened. That will put their pelvis neutral and help keep them aligned and from falling over to one side. In this way, all of their weight is not pulling on your body asymmetrically. This works best for smaller sized children. When carrying your child, rather than holding them out in front of you in both arms (say one arm under their upper back and one arm under their legs) which will put a lot of torque on your low back, consider coming in close and leaning their torso on the front of your body and holding them under the pelvis or legs.

Finally, I would like to touch on **lifting your child.** Again, it is best to try to get closer to the child's level by squatting or lunging. Keeping the child on a higher surface when starting the process is beneficial. Rather than bending over at your waist, get closer and bend your knees and hips, then lift with your legs extending and lunging. There are some key points of control when working with and lifting your child. They are the pelvis, hips and shoulders. If you can grasp your child under the shoulders, around to the back by the shoulder blades (or to their head if they do not have head control), you will have a firmer grasp and be using larger muscles on your body than your forearms and wrists. When you use these larger muscles, they distribute the force, and you have a better chance of not hurting yourself, as well as a better chance at having more endurance in the lift and carry. Likewise, if you can grasp at the pelvis and hips, you will have more control, and you will find that you have more strength and endurance for the lift without hurting yourself.

In conclusion, I would highly recommend that if you have a child with special needs that requires assistance to lift, carry and transfer, please consider beginning a short but effective fifteen-minute core strengthening and extremity stretching program to keep your body in basic shape. This will assist you so that you can continue to help your child without hurting yourself. What do we mean when we talk about strengthening your core? We don't just mean your abdominals. The core includes your glutes (buttock muscles), legs, and feet, as well as the alignment of your ribs to your pelvis. Tightness in your legs will prevent your back and legs from squatting and lunging properly and effectively. Your core muscles act as an anticipatory set of muscles to guard and protect your spine. Doing a fifteen-minute daily workout or working out at least five times a week is a much better alternative to suffering through hours of therapy and being in pain once you have hurt yourself. I know this can seem daunting in a day that probably already feels too short. The key is to find a time of day that will work every day and become part of your daily routine.

If you hurt yourself while attempting to carry or transfer your child, you will be harming your child by being unable to help them.

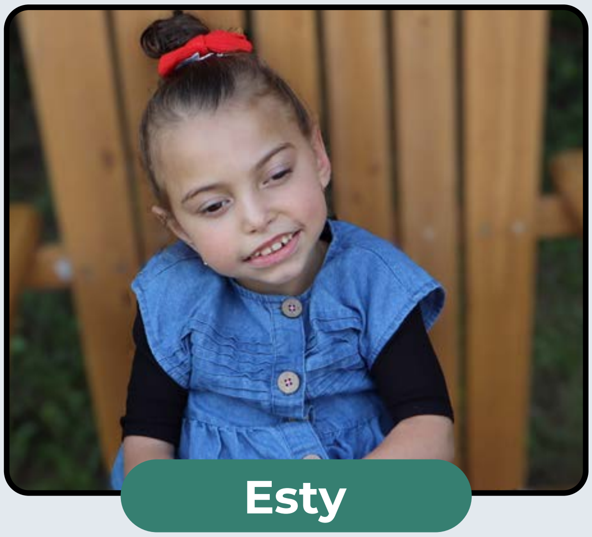
I sincerely hope this helps, at least a little, to lighten your load. I wish you every blessing and *Hashem's* help and guidance as you work to effectively carry and transfer your child throughout his day. ●

Rosetta DiTomasso has been a physical therapist for over 30 years. She shares with you some thoughts and ideas on the topic of lifting and carrying your child to hopefully help simplify and strengthen your day-to-day experiences.

Batsheva

Bracha Reitzel

Eizik



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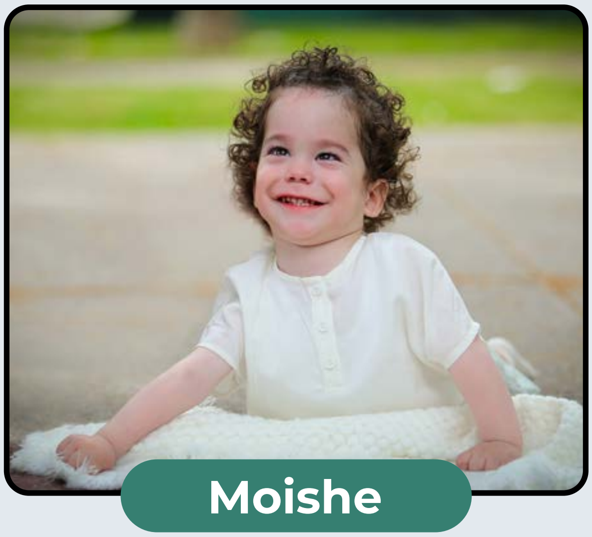

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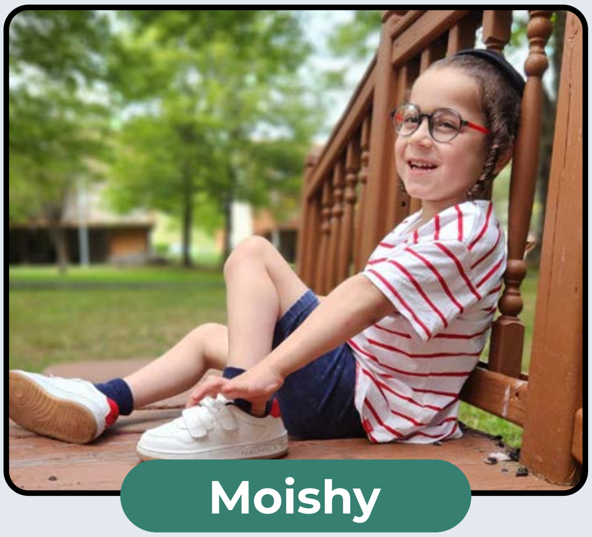

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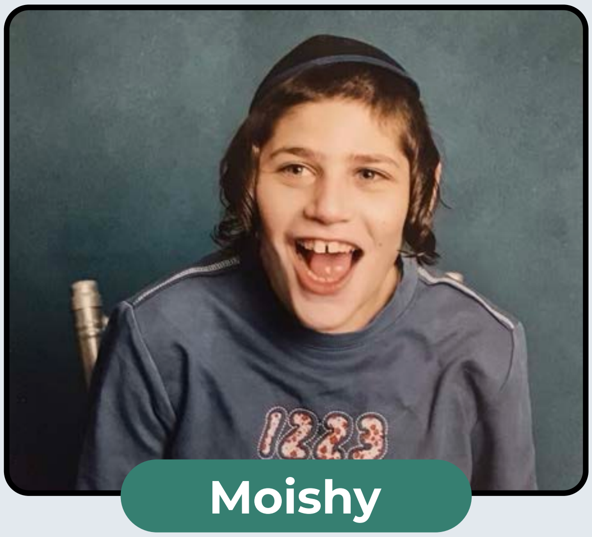

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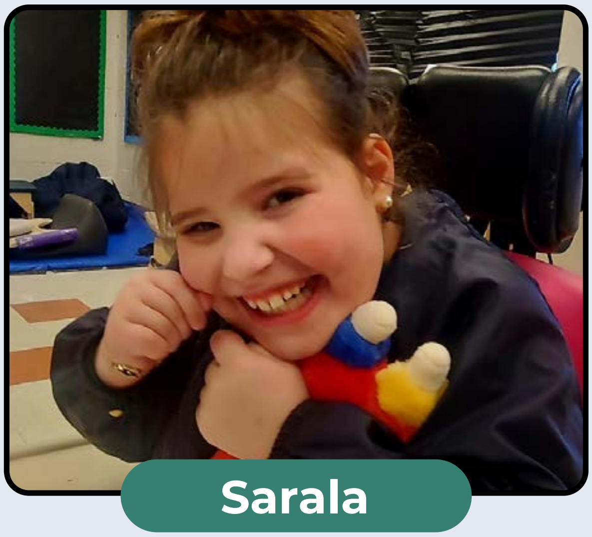

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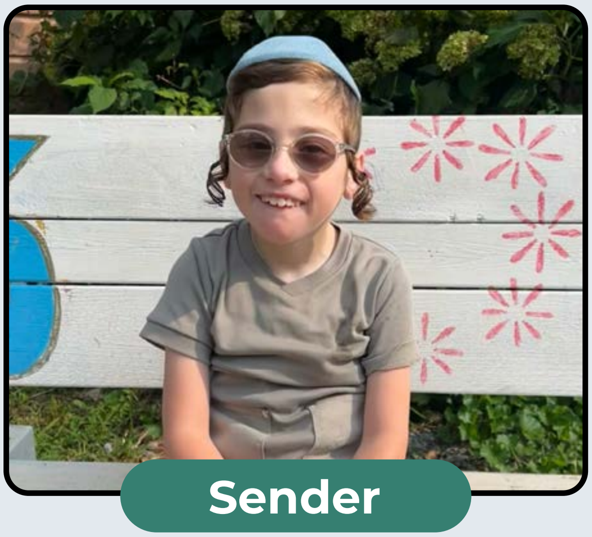

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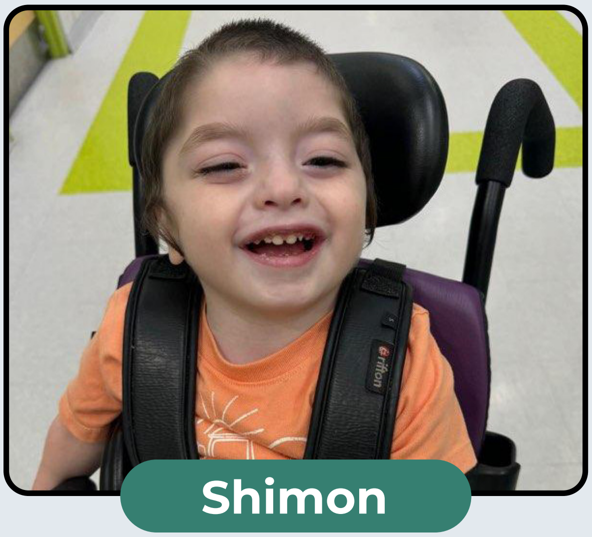

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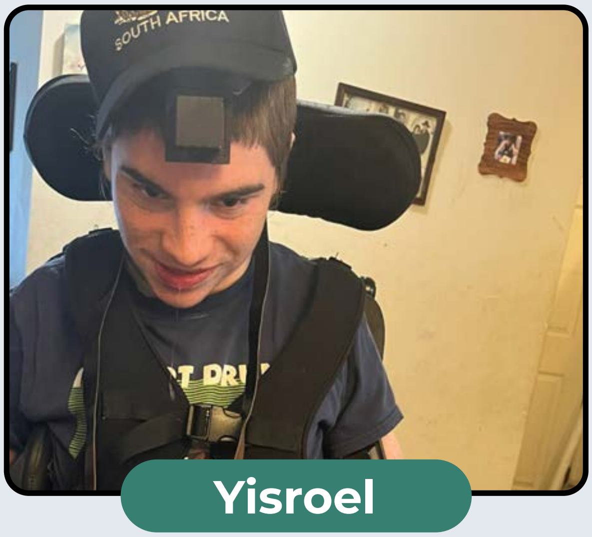

Yisroel

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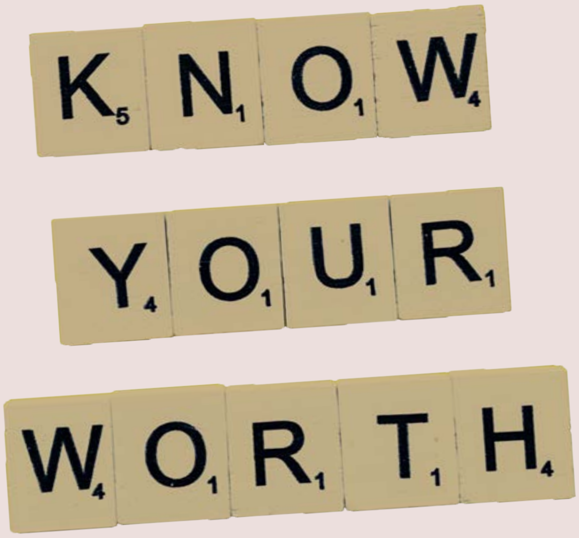
זכור ושמור · זכרהו על היין

BARUCH HASHEM ~ IT'S ~ SHABBOS

CHIZUK BOOST

Rabbi Shia Hershkowitz



The recent passing of the Kossove Rebbe, Reb Shraga Feivish Hager זצ"ל, has left a void in the collective hearts of *Klal Yisroel*. I'd like to share a story that illustrates just one of his attributes, which is his tremendous *ahavas yisroel*. The Kossove Rebbe, an outstanding *talmid chacham*, was a solid support for many downtrodden *yidden*. A group of parents and caregivers of special needs children sought his encouragement. During one of their visits, the *Rebbe*, with a unique and profound perspective, turned to the men in the room and said, "How fortunate you are. After your time in this world is over, *Hashem* will rejoice in the work that you achieved. Everything that you are doing to provide the best possible life for these נשמות טהורות is beloved in שמים."

This message is not just profound; it is life-changing. Let us realize how valuable our efforts are to *Hashem*! The Kossove Rebbe זצ"ל praised the accomplishments of those caring for the special needs population above all the numerous acts of selflessness he did for *K'lal Yisroel*. Let us reinforce in our hearts the immeasurable merit we gain by caring for individuals with special needs.

> Let us realize how valuable our efforts are to Hashem! Let us reinforce in our hearts the immeasurable merit we gain by caring for individuals with special needs.

Here is another story that demonstrates the value of our sacred mission in the eyes of *Hashem*. This story was told by a man named R' Hillel Furst. R' Hillel was overjoyed; his wife had just given birth to a beautiful baby girl, and he was about to share the happy news with the rest of his family. But the excitement leading up to the baby's birth quickly faded; their precious baby was born with several defects and would require specialized care her entire life. Their shock and grief quickly turned to near panic; how would they break the news to their teenagers eagerly awaiting a healthy new sibling? R' Hillel went to seek the guidance of R' Michel Zilber, the world-renowned *Rosh Yeshiva* in Yeshivas Z'vill. R' Hillel explained his situation to R' Michel and asked him to please break the news to his sons who were learning in the *yeshiva*.

"Before I say anything to your sons," R' Michel said, "I want to tell you about my family."

Surprised, R' Hillel nodded.

"Seventeen years ago," continued the *Rosh Yeshiva*, "my wife gave birth to our son. We love him dearly; he is a very special young man. In fact, he has special needs. Until very recently, my wife was our son's primary caregiver. But now he is a young man, and it is tough for my wife to shoulder his physical care on her own. Therefore, when she needs a hand, she calls me, and I rush home to help her, even if I have to leave the *yeshiva*. I do everything I can for our son, even the most unpleasant task of cleaning and bathing him. These moments with my son are my special *avodah*. I know he has a very *heilige neshama*, and I cherish the time I spend with him, serving him. When my son is clean and dressed, I get the feeling of *Motzei Yom Kippur* after *Ne'ilah*."

Noticing the shock on R' Hillel's face, he continued, "Although I am a *Rosh Yeshiva* and have many talmidim listening to my *shiurim*, I am not confident that leading a *yeshiva* is the ultimate *tafkid* that *Hashem* prepared for me. I am confident, without a doubt, that taking care of my son is exactly what *Hashem* wants me to do. That is my highest *tafkid* in this lifetime."

My late *rebbe*, Rav Moshe Wolfson זצ"ל, who passed away recently, used to say that every person comes down to earth to fulfill a specific task. There are two ways of figuring out what one's mission is. One way of recognizing our *tafkid* is by accepting that *Hashem* is the one who planted us in every specific situation. Another way is by noticing the particular hardships that come with each challenge. Parents of special needs children can easily recognize their *tafkid* in this world. *Hashem* chooses these unique, privileged, elite families to host these heilige *neshamos* while they are in this world. Only the most faithful, capable, and determined parents are entrusted with these deposits; these *neshamos* are the most precious diamonds. Mining diamonds is a most complicated and arduous task, yet *Dovid Hamelech* reminds us הזורים בדמאה ברינה יקצרו. Those who sow in tears will reap in joy. The harder the planting season, the sweeter the harvest! Rav Wolfson זצ"ל did the same as the חזון איש זצ"ל and stood up for individuals with special needs.

The parents of children with special needs play a unique and invaluable role in the Jewish nation. Their selfless dedication and love for their children testify to their strength and their special place in *Hashem's* eyes. We deeply value their commitment, which is a stellar example of love and selflessness, patience and determination. How fortunate is their share in גן עדן and in עולם הבא. Their *tafkid* is of the utmost importance in our nation. ●

Strength From a Higher Source

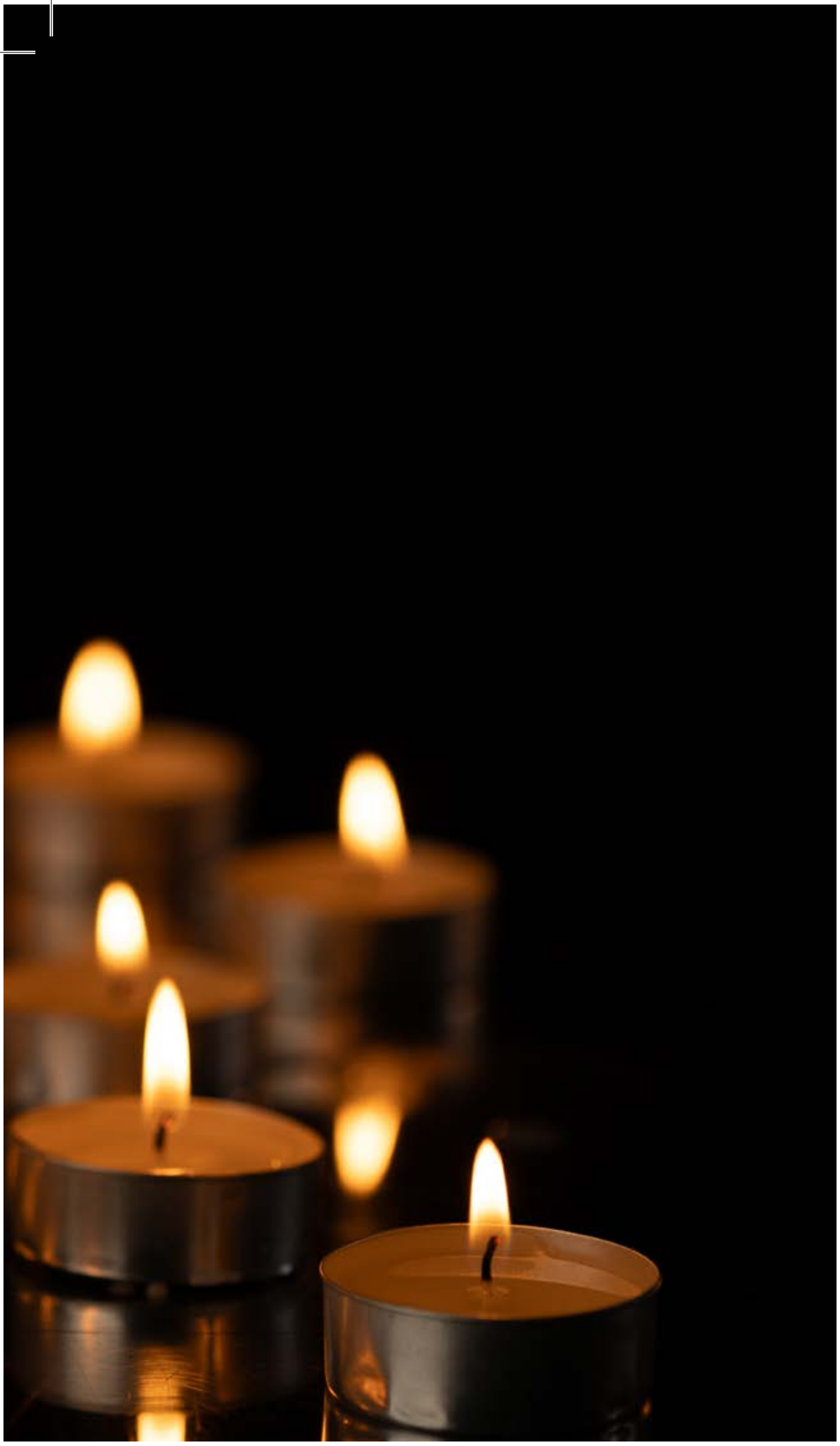
Rabbi Shimon Finkelman

My father a"h was forced into retirement in his forties due to a disability that made walking very difficult. For the next thirty years, my mother a"h was the breadwinner. She ran our home very efficiently, assisted my father with whatever he needed, and baked fresh *challos* for every *Shabbos*. She even served my father *chometz* on the morning of Erev *Pesach*!

Since he was basically homebound (except for twice a day, when someone walked him to *shul*), my father's life revolved around my mother. She worked as a bookkeeper some six blocks from our home. She walked home every day for lunch just to break up the day for my father. (Though he had *chavrusos* and attended a *shiur*, it still was hard for him to be at home all day.) My father felt great appreciation for all that my mother did for him. Every day when she came home at the end of her workday, she found a snack at her place at the kitchen table, along with freshly boiled water for her coffee.

As the years passed, my father's health declined, while my mother was in excellent health. The thought passed through my mind more than once that my mother would probably outlive my father because my father could not possibly cope without my mother at his side. Surely, *HaKadosh Baruch Hu* knew that better than me!

But that's not what happened. My father outlived my mother by nine years. He missed my mother terribly, but he did cope. He was surrounded by children and grandchildren, and he loved to learn *Torah*. But with all that,



he could not have managed if *Hashem* had not granted him the ability to cope.

That is how it is in every situation that might at first seem beyond our abilities to handle. It is said that with every child that is born, *Hashem* provides the *shefa* of *parnasah* that is needed to sustain that child. He also gives the mother and father the *kochos* they need to raise that child.

In Rabbi Nachman Seltzer's book 90 Minutes, on the history of United Hatzalah (in *Eretz Yisrael*) and its founder, Eli Beer, he tells of Eli's miraculous recovery from Covid in April of 2020. Eli had been fundraising in America when Covid hit, and he was hospitalized in Miami, where he had spent *Purim*. After being sedated for twenty-eight days, Eli woke up feeling very weak, somewhat disoriented, and sad to be so far away from his family. He was likewise quite dejected for having slept through all of *Pesach*.

When one of his friends in United Hatzalah's administration called him, Eli said that he did not think he had the physical or emotional strength to continue leading United Hatzalah. Others would have to take over.

His friend replied by informing Eli that when they heard how dire his situation was, United Hatzalah opened a special division as a *zechus* for his recovery. This division handled calls not for medical emergencies but for people who needed an act of *chesed*. They had responded to thousands of such calls. Eli's friend told him about just one of those calls:

An elderly woman called in with a request. She stated that she always lit fifteen candles for Shabbos and Yom Tov. It was Erev Pesach and she had run out of Shabbos candles. Could someone bring her candles?

A United Hatzalah volunteer responded to the call and knocked on the woman's door, bringing more than enough candles. The woman thanked him profusely, saying, "You saved my life." She explained:

"Ever since the Holocaust, I light one candle on Shabbos and Yom Tov for each of my family members who perished in the war. I was the only survivor. I have done this for many, many years. Today, when I realized that I had no more candles and that I could not go out and buy them, I could not imagine going into Yom Tov like this. I thought that if I were not able to light the candles, I would die from anguish. So, I feel that you saved my life."

When Eli Beer heard that such a *chesed* had been done as a *zechus* for his recovery, it infused him with new spirit. How could he not continue to lead United Hatzalah when the people who served under him had done such great things for his sake?

Just when an elderly Holocaust survivor thought that her life might be coming to an end, *Hashem* sent someone to bring her just what she needed. And just when Eli Beer thought that his great career as head of a lifesaving organization might be coming to an end, Hashem sent the story that he needed to hear.

On this past *Tishah B'Av*, Rav Elya Brudny spoke regarding the *tzaros* that *Klal Yisrael* has been enduring since this past *Simchas Torah*. He said that all of us must recognize that everything that happens is only because *HaKadosh Baruch Hu* wills it to happen. Our *emunah* is our strength, our comfort, in every situation.

There is another point to constantly bear in mind. *Dovid HaMelech* said: וְהַבּוֹטֵחַ בַּה׳ חֶסֶד יְסוֹבְבֶנּוּ, one who trusts in *Hashem* will be surrounded with kindness (*Tehillim* 32:10). The more we place our trust in the *Ribono shel Olam* the more we merit to see how He is leading us by the hand like a loving father, helping us to overcome the challenges that we face. May we merit to live each day with true *emunah* and *bitachon*. ●

No One Can Do What You Can

Shaindy Kleinman

Imagine if you were to wake up one morning and realize that there are absolutely no people to be found around you. You head out to the street, the stores, the *shuls*, the schools, and there isn't a human being in sight. Panic-stricken, you soon conclude that you are the only individual remaining on Planet Earth. You take a cup of water to revive yourself and hear a heavenly voice reverberating. "You're the only one alive, so make that *bracha* an extraordinary one." Can you imagine the quality of that *bracha*, made with proper intent and concentration? After all, you're the only one who can make *brachos* on the entire planet!

When you woke up this morning, *Baruch Hashem*, you were not alone, but living with approximately seven billion others. To *Hashem*, however, it's as if you are the only person in the universe, because only you can fulfill your specific mission in this world; the mission of helping your special child have the most incredible day and be the best that they can be. The world has waited all those centuries and millenniums for you to carry through that particular purpose.

The *Baal Shem Tov* teaches that every physical property contains *nitzotzos*, holy sparks. Each of us has our own custom-made sparks, reserved specifically for each person to discover and accumulate. They can be accumulated by many *mitzvos*. When you reach down to lift your child into her chair, call a new therapist to schedule an added intervention, or rush off to make a long-awaited doctor's appointment which will help your child medically, you are amassing holy sparks. No one can redeem your sparks, and you can't elevate anyone else's. When you understand your true value, identifying as a beloved, only child of *Hashem*, and you appreciate your inherent self-worth as a *cheilik Elokah mima'al* who is intent on helping your child with cerebral palsy, you won't ever be dependent on external boosts to feel encouraged. What really matters fundamentally is fulfilling *Hashem's* will. No wealth, popularity, or test score can affect that intrinsic truth. When you recognize the true worth of your *mitzvos*, your sparks, you can focus, not on what you need, but what you are needed for.

As a teacher, I imparted these two ideas to my students and asked them to write an essay expounding on the topic. One of my twelfth-grade students wrote, “A yid should never feel depressed or unbeloved by *Hashem* because *Hashem* recreates the world every second, and if you were superfluous, He wouldn’t create you again and again. If He’s keeping you here every moment, how you’re doing and what you’re doing is certainly relevant to Him.” Another student wrote, “Proof that *Hashem* loves you is that every detail of your life makes a difference to Him.”

Reb Chaim Shulem Deutch shlita, a renowned *mashpia* in *Yerushalayim*, posits, “It’s normal to wake up feeling sad or depressed (this was also the position of Harav Shlomo Wolbe, zatzal), but if immediately upon awakening you think, ‘I was created only to serve my Master,’ and you realize that you’re here for *Hashem*, and you live only for Him, you can adjust your sluggish sentiments.”

> *A yid should never feel depressed or unbeloved by Hashem because Hashem recreates the world every second, and if you were superfluous, He wouldn’t create you again and again. If He’s keeping you here every moment, how you’re doing and what you’re doing is certainly relevant to Him.*

The following story demonstrates the intrinsic value of every *Yid*, and, by virtue, the infinite worth of every single day that we experience with the challenges our children bring. In the 1500s, when czars reigned supreme, an indigent *Yid* was imprisoned for life in a dark dungeon. One day, the wicked czar had a change of heart and offered the inmate one day of freedom. The *Yid* wrote a letter to Reb Dovid ben Reb Shlomo Ibn Zimra, a renowned scholar, requesting guidance as to which day to choose. Reb Shlomo advised, “Choose the very next day!” When I asked my students what day the man should have chosen, their answers were invariably choices like *Yom Kippur, Shabbos, Purim, Pesach* or any other special day. These are good choices, but the very first opportunity to serve *Hashem* properly is *the* next available day to choose, even though it is rife with the difficulty of everyday existence. Every single moment in our lives is ripe with potential. How valuable each of us *Yidden* are! *Hashem* entrusted each of us with our own personal challenges and precious gifts and he knows we will do our best as we help our children each day.

As a lifeguard and water safety instructor for 30 years, I’ve taught many people between the ages of 5 and 75 how to swim, and I observed an interesting phenomenon. When swimming, if your head is too deep in the water, it creates friction as you move forward. Additionally, if you keep your head too high, your position is too vertical to make good progress. But if your head is in the right place – with your hairline parallel to the surface of the water – everything falls into place. The same is true in life. If your head is in the proper position, with thought processes that are optimistic, positive and *Torah’dig*, no matter how difficult the daily challenges are, you can make good progress forward.

What is that position? To know that you are rich. A rich man and a poor man both have good days and bad ones. On a good day, the rich man executes a million-dollar deal. On a bad day, he loses millions. But even on an unprofitable day during a losing streak, he nevertheless considers himself rich. Being rich is his identity.

Conversely, the poor man might serendipitously earn $100 on a good day, but his identity is that of a pauper. You need to know you are rich, merely by virtue of being a piece of G-dliness, and if you internalize this eternal truth, you don’t measure your identity by what people around you say and do, but by *Hashem’s* barometer. The *Rebbe* of Lubavitch, *zatzal*, famously advised, “Don’t think what other people are thinking and saying about you. Doing that just pulls you down and creates needless anxiety.”

Instead, choose to believe in the G-dliness *Hashem* invested in you, and every morning when you wake up; think, “If my faith in *Hashem* doesn’t get me out of bed, how about *Hashem’s* faith in me to care and help my child?” The only genuine solution-oriented self-encouragement that has eternal value is the recognition that you have a unique mission in this world, and that everything that happens to you is because it is necessary for your purpose here. Our children and families grow and build themselves up through our efforts. With this perspective, you generate much *syata d’Shmaya* and create a *Kiddush Hashem* while caring for your child in your home, your school, your community and your world. ●

A Dream Redefined

Anonymous

For so many years we cried and prayed
Yearning for a child
Then *Hashem* gave us this miracle
We weren't "that couple" without kids anymore
She was the child that made us feel like we belong
She's the child that I breathe for
Yet the pain is still raw

My heart wrenches when she notices she's different
She's so young, yet she understands so much
It's a constant struggle of
Am I teaching her resilience
Or am I pushing her too hard?
This is not what I signed up for
Yet she's the child that I breathe for

She's kindhearted
Her smile makes my heart flutter
When I see how she's similar to me
I am filled with joy
Her good morning tune and good night kiss
Are what I dreamed for all these years ago
When she "helps" me in the kitchen
Together we're a team
It's us against the world
In those moments
I feel like we can conquer anything life has in store

This isn't how I had imagined it would be
Yet she's the child that I breathe for

Abbott

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*No significant difference has been shown between milk derived from rbST-treated and non-rbST-treated cows

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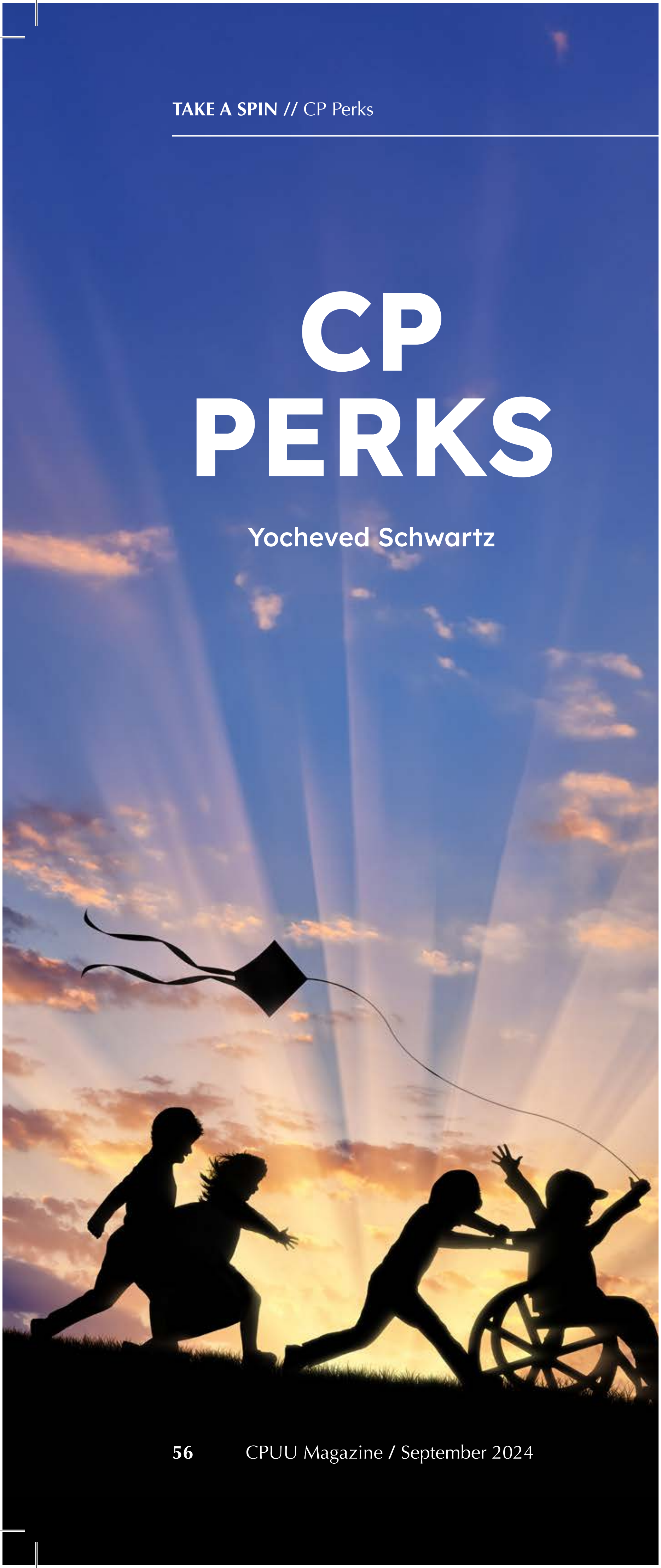
CP PERKS

Yocheved Schwartz



Yes. It was true; honest-to-goodness, really true. Our family, you know, the one that never, ever wins anything, had actually won a dream vacation to Florida!

We got to stay in the most picturesque villa, appropriately named "House of Dreams", framed by large glass windows and doors on all sides to allow in the Florida sun and scenic views. There were many sitting areas, with comfy couches, cozy throw pillows, fuzzy afghans and - an 'egg chair'! ("Heaven!" the kids crooned.)

The house was fully stocked with all amenities we could dream of, and some we couldn't. The pantry was packed with basics and goodies galore. All *Shabbos* needs were fully taken care of and every need anyone could possibly have was thought of and arranged.

There was a playroom with toys and games, crayons and coloring books; a garage with a pool table, tennis and basketball sets; a Jacuzzi, and of course, our very own heated backyard pool, surrounded with palm trees and well-tended, beautiful landscaping. An outdoor lounge, a swing set, a full outdoor kitchen, and a canal running right behind the property completed the picture.

So, how ever did a Plain Jane kind of family like ours reach such luxurious heights? How did a stay-at-home, Brooklyn born-and-bred family whose farthest excursion was to their Catskills bungalow colony get to explore the parks and attractions in the Sunny State?

I will let you in on the answer. It's a small 2 letter word called CP.

Ever since our precious *yingele* has joined our family some 8 years ago, our family has been enhanced with many new experiences; some more challenging and some even more so, but all enriching our lives and causing us to grow and stretch in ways we couldn't have imagined previously.

So, when Heavenly orchestrated events led us to try a new therapy program in Florida, it was by no means an easy undertaking. We chose to focus, however, on the pampered, cared for feeling of having someone arranging every last detail for us.

And so, we were indeed the winners of the greatest lottery of all! ●

SPOT OF DREAMS

Welcoming All Children

Our Dream

At Spot of Dreams, our goal is to help guide every child to find the strength and confidence within themselves.

With our unique inclusive classes, we target many useful skills and abilities that will help your child throughout their formative years of growth and education.

Our programs cater to mainstream children as well as children with challenges.

Hours:

Sunday:

9:00 AM – 12:00 PM

12:30 PM – 3:30 PM

Monday – Thursday:

4:00 PM – 7:00 PM

*Open on ALL Legal Holiday

Contact Info

We would love to hear from you!

✉ info.spotofdreams@gmail.com

🌐 www.spotofdreams.com

What We Offer:

Baking

Through unique team building exercises, your child will learn to work together for a common goal, explore the science in baking, and have fun.

Yoga

Kids will learn how to reduce stress and improve concentration, mood balance and flexibility. Best of all, kids think yoga is fun!

Art

Let your kids experiment with materials, learn techniques, express themselves, explore their own hidden talents, and enjoy art!

Music

Kids will be guided to explore, enjoy and understand concepts of music. They will also learn to follow directions through music, movement and fun.

Home Modifications

Varda Neuhaus, PT
Debbie Kupfer, PT

HOYER LIFT

Modifying your home for a child or adult with disabilities is crucial for fostering their independence, safety, and overall well-being. Tailoring your living space to accommodate their specific needs can significantly enhance their quality of life by ensuring that they can navigate their environment comfortably and safely. Adaptations such as installing ramps, widening doorways, or modifying bathrooms can prevent accidents and make daily routines more manageable. Moreover, a thoughtfully designed space promotes a sense of independence and fosters healthy self-esteem, allowing the child to engage in activities with greater ease and confidence. Ultimately, these modifications not only support the child's physical needs, but also contribute to their emotional and psychological development, creating a nurturing environment where they can thrive.

If you're handy and can tackle simple renovations yourself, you can find a variety of helpful items at stores like Home Depot, Lowe's, or even Amazon. Essential modifications such as grab bars, door handles or levers, light switches, and virtual assistant technology like Google Home or Alexa can be easily purchased and installed to enhance accessibility. For more extensive renovations, such as installing ramps, lifts, or making significant bathroom modifications, you'll need to hire contractors or specialized providers. We generally recommend Gavriel Gozland at ShabbosLift Solutions for stair glides and lifts, but it's important to explore other providers as well. Be sure to vet any potential contractors thoroughly, by checking references to ensure you choose a reliable and qualified professional for your home improvements.

You can enlist the help of handymen, plumbers, and general contractors to assist with your home renovations. Additionally, social workers and local organizations such as Hamaspik or Yedei Chessed can be invaluable resources for finding funding to support these projects. There are also home modification specialists who can assess your home, design effective solutions tailored to your needs, and even help you find suitable contractors. Generally, these specialists, like my partner and I, are physical or occupational therapists with years of experience in home modification. They have assisted actual people in navigating their home with a variety of physical limitations, so that they could achieve a higher, more independent level of functional mobility.

We've outlined some common home modifications and provided a list of potential resources to help with funding. While securing financial support can be challenging, don't be discouraged. By reaching out to local building departments, social workers, charitable organizations, and *chessed* entities, you can explore the most cost-effective ways to adapt your home. These resources can assist you in navigating the funding process and finding solutions that will make you and your child's life more comfortable and stress-free. With persistence and support, you can create a more accessible and welcoming environment tailored to your needs.

THESE MODIFICATIONS NOT ONLY SUPPORT THE CHILD'S PHYSICAL NEEDS, BUT ALSO CONTRIBUTE TO THEIR EMOTIONAL AND PSYCHOLOGICAL DEVELOPMENT

HOME ACCESSIBILITY IDEAS

Access in and out of home

Stair glides
straight away $3,000
custom glide $10,000-$15,000

Elevators
Indoor $25,000- $40,000
Outdoor vertical lift $6,000-$9,000
Outdoor elevators $15,000-$20,000

Ramps
portable ramps $100-$1,000
permanent ramps $10,000-$15,000

Motorized Stair Chairs

LINE2design-USA
Motorized Mobile Stair Lift Climber
line2ems.com | 909-798-1829
$1,379-$1,599

The LINE2design Motorized Mobile Stair Lift Climber allows you to provide safe transport for patients up and down stairs.

The Battery Powered Lift Track Stair Chair has a power track system that makes transporting patients up and down stairs an easy task. The motorized track system provides controlled transportation up and down stairs. When operating this chair, the power tracks make contact with the stairs, allowing the chair to glide over the edge of the stairs, thus eliminating the need to lift the patient and chair. The LINE2design Stair Lift Stair Chair can be used for medical transport, emergency evacuations, and daily assistance going up and down stairs.

Mobile Stairlifts
Mobilestairlift.com | (212) 366-5483

1. Genesis Mobile Stairlift $2,999

The Genesis from Mobile Stairlift is your go-to solution for safe and efficient stair navigation. This stairlift chair makes it easy to transport individuals up to 120 flights of stairs on a single charge, handling up to 400 pounds while weighing just 62 pounds. It is the perfect combination of power and versatility, making it dependable and easy to use and store.

The Genesis Mobile Stairlift Chair also prioritizes patient and operator safety. It features a padded upper control handle, rear and lower handles for comfortable maneuvering, and an anti-slip Ultra Grip track system so you and your loved ones can move around safely and confidently.

2.Genesis Eco Mobile Stairlift $1,999

Our Genesis Mobile Stairlifts are a budget-friendly solution for safe and efficient stair navigation. The lightweight but durable design offers a 250-pound lift capacity despite only weighing 62 pounds. A single charge makes it possible to go up and down 40 flights of stairs.

Designed for safe portability, the Genesis Eco Mobile Stairlift is easy to maneuver and store and has top-rated safety features, such as a padded grip on the upper control handle and front-rear handles for added support. The mobile stairlift's dual-locking wheels prevent unwanted movement when stationary, and the anti-slip rubber tracks ensure optimal control during use.

ShabbosLift Solutions

shabboslift.com | (855) 742-2543 (646) 543-8811

ShabbosLift Solutions is a full-fledged boutique provider of stairlifts, wheelchair lifts, and home elevators with a mobility *Shabbos* mode.

Patient Lifts

A patient lift is designed for transferring patients from one location to another, such as from a bed to a chair, or from a chair to a bath. They can be powered manually or with an electrical power source.

hoyerlift.com

1800Wheelchair.com| (800)-320-7140

baronmedical.com | 718-486-6164

medmartonline.com | (888)-257-2024

OUTDOOR ELEVATOR

amazon.com

1. Basic manual model $400- $500
2. Electric unit (Uses rechargeable batteries or plugs into a wall outlet) $3,000
3. Motorized ceiling-mounted models $20,000 or more (factoring in installation costs).

Widen doorways

36 inch minimum or reverse or offset the hinges.

Restore Floors

Restore hardwood floors or replace carpets to industrial flatter carpets ensure floors are level and slip proof.

Grab bars

Grab bars in bathrooms, and anywhere else that client would require i.e. in the bedroom for dressing

Door handles

Replace door handles with lever doorknobs

Google home/Alexa

Install google home/Alexa to aid in turning lights on and off or other necessary electrical devices

Roll in showers

Complete remodel for accessibility
$15,000-$20,000

Cut out in bathtub

$1,800-$2,000

Roll under sinks/ counter

Raised toilets/bidets

Full turn around space for wheelchair

Wheelchair height

Wheelchair height counters, shelves, closet access, table height, outlets, light switches, appliances i.e. microwave at wheelchair height.

Modifications for sensory issues

Soundproofing rooms, adjusting lighting levels, calming paint colors for sensory issues

RESOURCES FOR FUNDING HOME MODIFICATIONS

Rebuilding Together

rebuildingtogether.org | (202) 518-3100

Rebuilding Together is an American non-profit organization with a mission to repair the homes of people in need and revitalize our communities.

Habitat for Humanity
habitat.org | (800) 461-9330

Habitat for Humanity in your town. Habitat for Humanity is a nonprofit organization that helps families build and improve places to call home. We believe affordable housing plays a critical role in strong and stable communities. At Habitat, we partner with families, communities and local organizations across the U.S. to help people with disabilities improve their homes and their quality of life so they can flourish where they live.

The Children's Hemiplegia & Stroke Association
chasa.org | (817) 492-4325

CHASA is a nonprofit organization dedicated to improving the lives of infants, children, young adults and families that are affected by pediatric stroke and other brain injuries that result in hemiplegia, hemiparesis, or hemiplegic cerebral palsy. Their website offers support and information, state grants for home modifications and adapted vehicles. Search for your state's vocational rehabilitation department.

The Mobility Resource
themobilityresource.com | (866) 771-7770

The Mobility Resource provides a list of rebates and reimbursements and state specific disability grant resources

Special Kids Fund Childrens Charity/MagicMobility
specialkidsfund.org

Special Kids Fund is a nonprofit that is best known for its national wheelchair van assistance program, MagicMobility Vans.

Wheelchairs 4 Kids
wheelchairs4kids.org
(727)-946-0963

Wheelchairs 4 Kids is a nonprofit organization for wheelchairs, home and vehicle modifications, and assistive devices for kids.

National Directory of Home Modification and Repair resources
Homemods.org

This Directory provides home modification and repair resources (such as featured programs, funding, service providers, and consumer materials) for each state.

Medicaid Home and Community-Based Services Waiver Program

Medicaid waiver home aide program. OPWDD administers this HCBS Waiver. These services can include habilitation services, respite care, service coordination, and adaptive technologies.

Home Advisor
homeadvisor.com

Home Advisor has a disability accommodation for home adaptations for individuals with disabilities.

Ramps.org

Resources for programs around the country that help build and pay for ramps.

Oracle Health Foundation
oraclehealthfoundation.org | 816-573-6050

Oracle Health Foundation is a nonprofit that delivers pediatric grants and school-based wellness programs. The pediatric grants cover a wide variety of clinical, equipment, travel and lodging, and vehicle modification costs related to children's healthcare needs. ●

Varda Neuhaus, PT
Debbie Kupfer, PT
Tristate Home Safety Modifications | 845.216.2219

MOTORIZED STAIR CHAIR

Your Take

A parent reached out with the following question:

We're looking into different therapies for my daughter, I think hearing more information from others and what worked best for their child (with CP) is the best research, rather than having a PT's personal opinion.

Would you share which type of therapy and which therapists you felt worked most for your child in helping them reach functional activity like learning to walk unsupported?

There are so many things I've heard of, and I'm not sure if they are worth trying without a good reference. Some examples of possible therapies that we would like to learn more about are Medek Therapy, E-stim, Aqua Therapy, and Barwis Fl-hyperbaric Oxygen.

Here are your responses:

I have found that the most beneficial therapies have been e-stim and hyperbaric 02 These are provided by an excellent therapist. I have found that Florida based therapists are quite effective.

Most New York therapists work on "Massage" and "passive range of motion" They make. "Clinical" decisions to refrain from aggressive therapy.

In Florida, the mindset is very different. The therapists work on having my daughter up and about consistently. She takes steps on her own in the gait trainer and walks with assistance in the pool. It's quite different from New York, where I found the therapists were pessimistic. In Florida the can-do attitude is infectious & progress is being made.

Kol Tov!

IIIIIII

My daughter is not up to walking, but we saw a lot of progress with Medek sessions done almost daily. She learned head control, and to balance herself to a certain extent. We stopped doing the sessions when she outgrew EI but would love to continue. I think she would benefit a lot if we could continue Medek sessions in the future.

IIIIIII

I've had a great and very successful experience with Yides Winstock in Monroe.

She is very knowledgeable and experienced and works with several different modalities.

IIIIIII

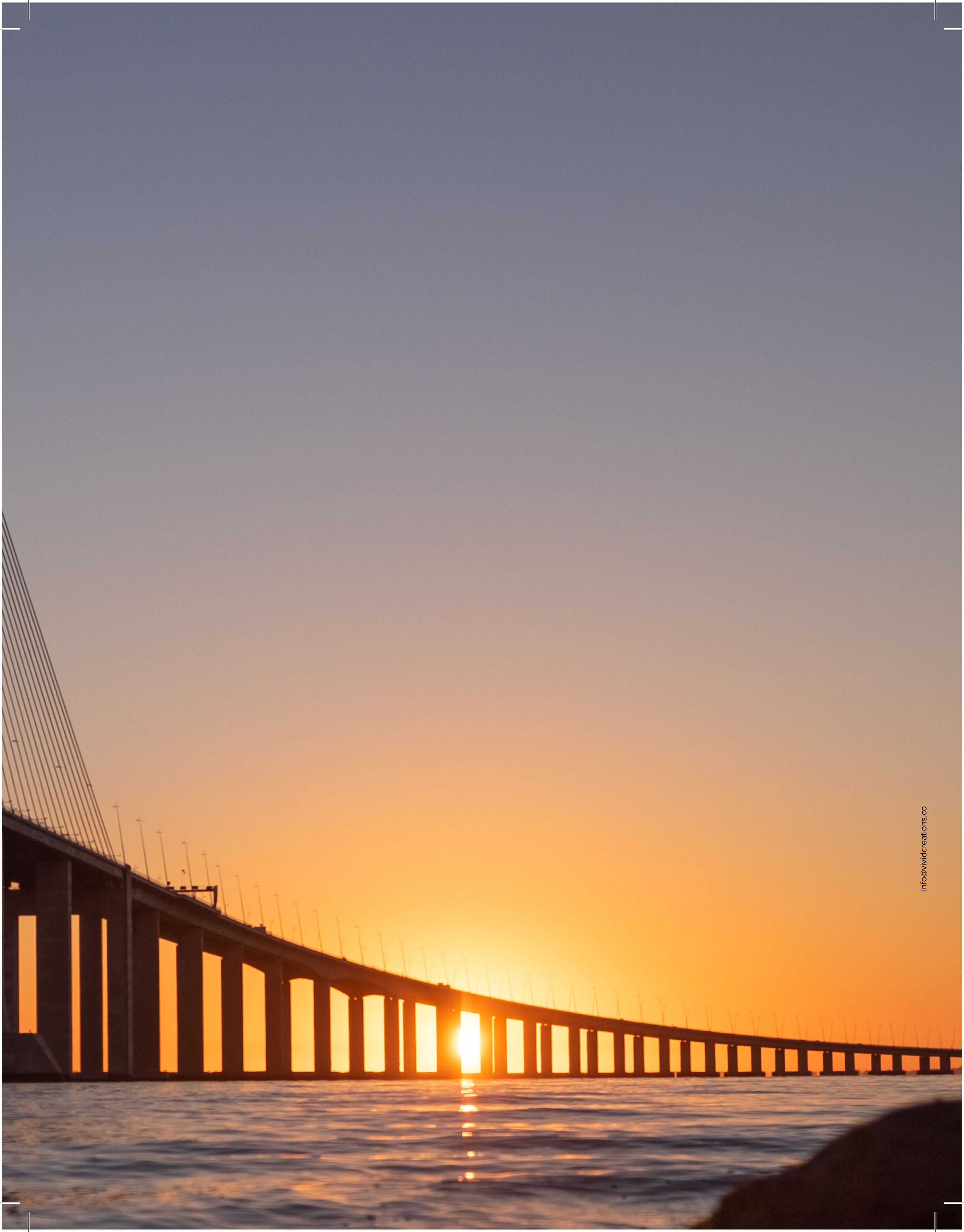
Cranial, MNRI and the Anat Baniel Method have been a great complement to the more intense PT that my Gitty had. I am hearing more about E-stim and TMR and I hope to try that in September IYH.

The interviews on the Nishmoiseini hotline 'mastering methods and modalities' might also be helpful. You can hear them on 718-759-1111 Press 3 then 2 and then follow the prompts for the specific type of therapy that you want to know more about. The main thing is to daven for *siyata dishmaya* and for the right *sheluchim*! Loads of *hatzlocha...*

IIIIIII

Some of the therapies I find really helpful for my son in addition to good quality physical therapy are Aqua, Feldenkreis and hippo therapy (horse) for those hips. ●

Cartoon Corner



info@vividcreations.co