CPUU
Cerebral Palsy Unites Us

ISSUE 5 - MARCH 2025

UNITING FAMILIES AS WE CROSS BRIDGES TOGETHER

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Note: This magazine contains Divrei Torah.

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Editorial

Hello and a *Freilichen* Purim!

I am very excited to present the fifth edition of CPUU Magazine just in time for Purim. Purim this year is unique and 'special' because it falls out on Friday. The *mitzvos* of Purim move with us straight into *Kedushas Shabbos*. All the *mitzvos* of Purim and all the merriment are squeezed into a short Friday, making it a **C**oncentrated **P**urim!

Speaking of Erev Shabbos reminds me of a Shabbos *aufruf* story, I recently heard. Yankele was very excited to go to *shul*, but it was very hard to sit quietly and be patient until the end of *Shacharis*. This Shabbos was his older brother's *aufruf*, and after his brother had an *aliyah*, there would be pekelach! His big brother approached the *bimah*, said the *brachos*, and after the *Ba'al Koreh* read the *parsha*, chaos erupted. Pekelach rained down from the *Ezras Nashim*, and poor Yankele was shoved from one side to another and then knocked to the ground as the bigger boys dashed forward and snatched the *pekelach*.

After all his attempts, Yankele did not get even one *pekela* and was inconsolable! His crying was so loud and intense that it reached the ears of the *Rav*, who worriedly asked "Why is this child crying so hysterically?" The men explained him, that the child is in tears simply because he wasn't successful in getting a *pekela* and that's why he's crying.

When the Rav heard, he remarked "How interesting, I get so many calls from people crying that they have a *pekela*- and Yankele's crying because he didn't get a *pekela*?!"

"Nothing to worry, the Rav continued. He'll get older and he'll get his *pekel* too!"

This anecdote carries a vital message. Often, we think we are the only ones with this problem or the other. We've all got a *pekel* or two; some are obvious, and others are not. We are all carrying something. Some people can hide their burdens in bright, colorful bags, while others must carry theirs in clear ones. Even more so, it might be a good idea to peek inside our own *pekel* and find the goodies hiding there. You'd be surprised to see that there are!

What matters most is how we embrace our *pekel*. Do we let ourselves be knocked down, stay down and cry, or we look upward, remembering who is throwing them down at us, and embrace them with joy!

Let us remember, our carefully planned *mishloach manos* packages get filled with sweets and love; similarly, our real *life* pekel is carefully designed, filled with sweets, and delivered personally by our loving Father, especially for us.

Wishing you all a *Freilichen* **C**oncentrated **P**urim! ●

The Publishers

Inbox

Hi! We got the magazine and it is beautiful! Cover to cover! Great range of articles! *Kol Hakavod!* Would it be possible to purchase a few extra copies? I would love to send it to some of the camps/schools Michal mentioned in her article, as well as have 2-3 extra for proud Savtas. Please let me know!
Thanks so much,
Malky Tannenbaum Haimoff

What I find unbelievable about the magazine is how many times I can reread it and get *chizuk* and even more information each time. Thank you so much for all the hard work. I love it!
Rochma Beily Lipschitz

Hi, On a quick note, I scanned the mag and it's absolutely amazing to see how much you have grown since the last issue. I obviously spent some time looking at the picture and it was cute to see so many new faces and so many kids that I actually know. The magazine looks very interesting, full of content, enjoyable, and professional. Can't wait to read it from cover to cover!!!!
Rivky Freund

It's beautiful!! *Chazak ve'amatz!*
Perry Binet

Thank you for sending. It's a *zechus* to have a small share in the wonderful work of this *choshuva* organization.
Rabbi Shimon Finkelman

Thanx loads!!! Yay!!!! Thank you so much!!!! I look forward to reading it!!!! Love getting it and especially seeing my yummy brother in there!!! It's a beautiful magazine!
Elky Kind

Hi, I would like to take the opportunity to commend you on an awesome awe-inspiring magazine! It didn't miss a detail! From *hashkafa* to therapy to personal stories to *chizuk* you covered everything!!! *HaKadosh Baruch Hu* should give you the *koach* to continue to do this amazing work!
Chavy Freier

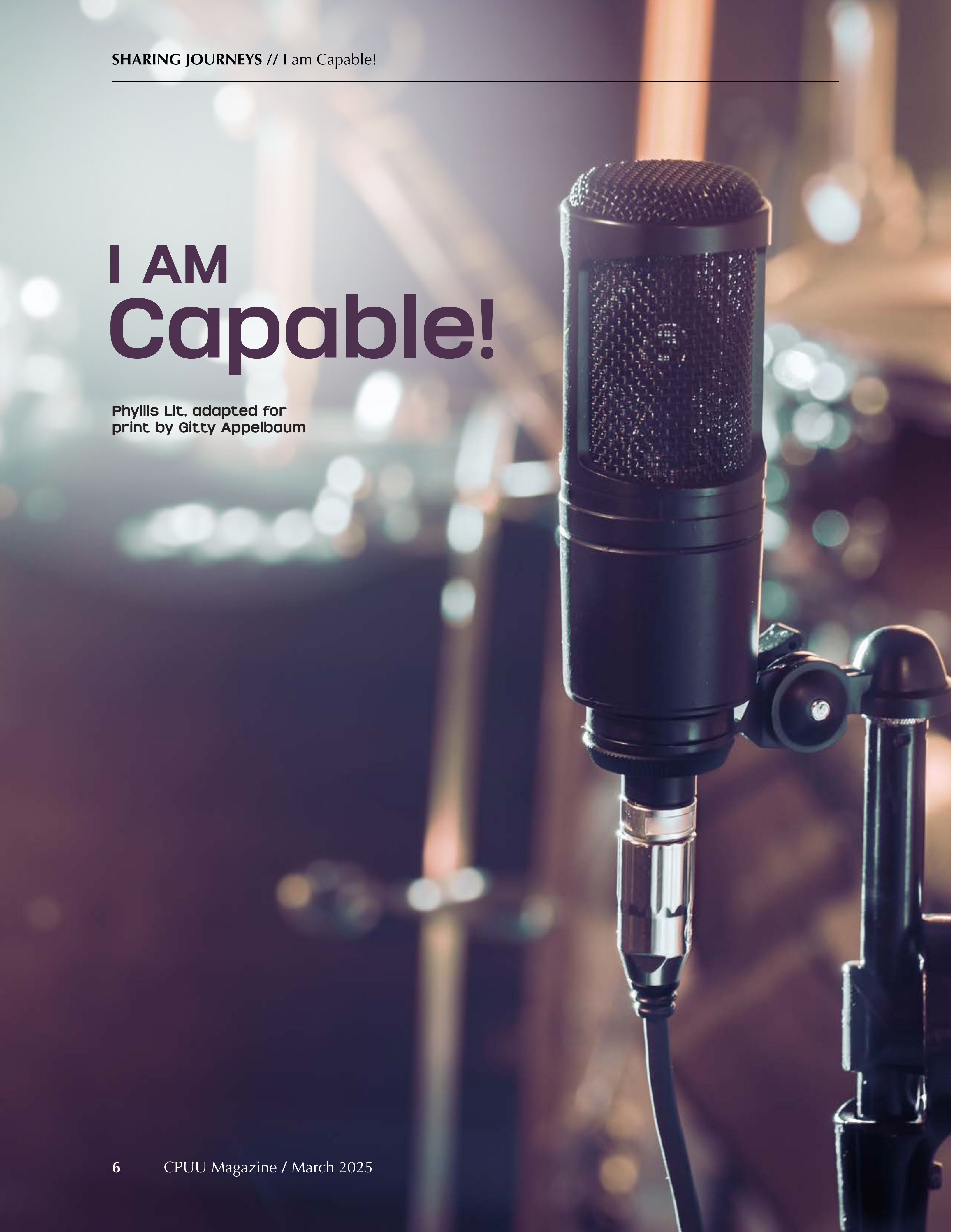
What a beautiful magazine. Thank you so much for putting this together so our families with CP can feel that they truly belong!
Tova Wacholder,
Program Director, Yahalom NY

I just read Reb Shia Hershkowitz's incredible article in issue 4. The tears are streaming down my face. I know I coproduce the Neshamela magazine and have plenty of opportunities to give *chizuk* to others. But lately, with Yehuda almost turning sixteen, I grapple with a lot of things. One thing that hit me recently is that people are afraid of him. Naturally they should be as he is close to six feet tall at this point. B"H we know there is nothing to be afraid of. Reading this article gave me such deep, much needed *chizuk*.
Fraydel Dickstein

A *guten erev* Shabbos!! Wanted to say that I really appreciated your magazine! It's the perfect blend of *chizuk* and hope and also informative.
Thank you and good Shabbos!!
Kol Tov!
Rachel Zimmerman

Hello, I came across an interview about your magazine on the 'Nishmoseine' hotline, and was really inspired. I have a 3-year-old daughter with a cerebral palsy diagnosis, and would love to receive the magazine. I do live in the UK, so I'm wondering if you have international subscribers. Looking forward to hearing from you.
Loads of Hatzlacha!
P. R.

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



I AM Capable!

Phyllis Lit, adapted for print by Gitty Appelbaum

If you had told me fifty years ago that I'd inspire people with my story, I would never have believed you. You see, when I was born, people didn't know what to do with children who were disabled. Very often, such children were hidden away, and doctors were unsure what diagnosis or label to give. I'm so grateful for the people in my life who saw past my disabilities and didn't let labels define me.

My name is Phyllis Lit, and I was born in Philadelphia with Cerebral Palsy. I currently live in Ateret Avot residence, which is located in Flatbush, New York. In the early years, it was very hard for me to understand why I was different from everyone else. I didn't want to put up with taunts and teases about being disabled. I just wanted to be like the "regular" kids and go to a "regular" school. I felt punished, and I was sure *Hashem* didn't love me. I questioned why I, a *frum* child, was unhealthy, and my neighbors, who were not *frum*, were healthy. How could it be? With time, I came to recognize my limitations as a gift. A gift that brought me closer to *Hashem* and developed me into the person I am today.

> **Surround yourself with people who believe in you.**

I was sent to a non-Jewish school for challenged children and was often hit by other kids who were there. These were my hardest years, during which I felt lonely and abandoned and only got to see my mother once a week. It was during this time that I met two special people who worked at my school, Mrs. Cohen and Mrs. Harmon. They were both Jewish and because I was Jewish too, they took a special interest in me, helping me during the two years I was there. I realized then that *Hashem* was looking out for me and had sent these two Jewish women to work in a non-Jewish school, especially for me! He didn't abandon me. In fact, He was taking care of me like only a father can!

Mrs. Cohen had read an article about music therapy and thought it would be a helpful modality for me to try. She was right, and after trying music therapy, I was a changed child. No longer was I the shy, timid girl who sat in the corner. Music brought out the best in me. Hearing the recording of myself singing filled me with a warm feeling and when other people heard it, they couldn't believe it was me!

After two years, my parents realized that this school wasn't meeting my needs and felt it was time for a change. With financial assistance from the government, they founded a small private school called Delta. Here, I had a fantastic teacher who built me up like no one had. He was dedicated, enthusiastic, and funny, and when I'd laugh at his jokes, he would tell me I was too smart for his class. He found ways to help me remember what I learned and tested me using games he knew I liked to play. Instead of testing my spelling with the standard spelling quiz, he'd test me through the game of Jeopardy. He saw the person beneath the physical and neurological limitations, and having my worth recognized raised my self-esteem to new heights.

Shortly after I left the old school, Mrs. Cohen called. She felt bad that she never said a proper goodbye, and we arranged to meet again. *Hashem* orchestrated this perfectly, as He does with every other aspect of my life. That meeting strengthened our relationship, and when my mother got sick a couple of months later, Mrs. Cohen took me in and cared for me, driving me back and forth to visit my mother in the hospital.

Although it was hard for me at times, I recognize now that *Hashem* always had my back and constantly sent me friends and people who believed in me. With time, as I grew through my challenges, my *Emunah* was strengthened, and so was my *Yiddishkeit*.

With the incredible advances in technology over the years, I'm able to do so many things that once were impossible. I can be connected to the outside world without the trouble it takes to get out. I can access libraries and read books even though I'm visually impaired. I can go shopping and place orders, getting the necessities I need despite being physically limited. There are also special apps that act as reminders, keeping track of my medications and appointments and reminding me if a phone call needs to be made or a prescription refilled. I've learned to use voice commands, which can sometimes be frustrating, as the app has a hard time understanding what I say because I sometimes stumble over my words. I learned to view this as a blessing and accept the learning curve each new technology brings as it helps me so much in my day-to-day life and encourages me to try harder.

With each day that goes by, I'm grateful. Grateful for the progress I've made and how far I've come. Grateful for the people who helped me along the way and empowered me. Grateful for the opportunity to inspire people with my story and ignite hope in the hearts of children and parents who are faced with a diagnosis of Cerebral Palsy. If I could have all the people who have helped me in one room, I don't think I could adequately thank them for all they have done for me. They've enriched my life in so many ways.

For all those struggling with CP, there's a message I want to share. You might be struggling; you might be wondering why *Hashem* chose this for you. You might feel like there's nothing substantial you can contribute to this world, but all that is not true! Surround yourself with people who believe in you. Test your abilities and push past things you thought you could never do. Try something you think you'll enjoy and never stop spreading your light to those around you. ●

Limited Edition

Y. K.

As long as I can remember, I always liked to be original.

I don't necessarily know why, but it's so me. You know that plaid H&M shirt many *heimish* families bought in the winter of 2001? When I found out that four of my classmates had them, I stopped wearing them. It wasn't original anymore, so it became boring.

As a teen, I remember buying a bright blue gorgeous wool coat that everyone complimented me on. It just matched my eyes so well." Where did you buy it from?" everyone kept asking. But the best compliment was when someone was drooling over it. They thought it was so different, yet so gorgeous. They all wanted a piece like it too. Just like buying that coat, whenever I shopped, my mind simply went back to that original sweater, dress, or jewelry piece. How I loved the feeling of being original!

What made me think of this recently was that I was deeply pained when a neighbor commented, "Because both of our kids are still young, they don't notice that your child is different."

So let me tell you, because I couldn't tell her. I couldn't and wouldn't explain it to her. Somehow, this interaction brought me the clarity I needed to view my child.

My child isn't different. The word "different" has an existing negative connotation. I will not be in denial yet choose to think of her as an "original"!

She's original, just like that gorgeous bright blue coat that no one in my high school owned. The one everyone was drooling over because they knew how original it was. Everyone was wondering where they could also find such a gorgeous unique coat.

She's that original!!!

My daughter isn't like yours. She's a limited edition. She's the one that will make anyone reconsider what it would be like to have a child with a unique challenge. She's known to be the cutest kid in school that all other classroom teachers look for in the hallway! Her teachers and therapists drool over her, she's very intuitive, and knowledgeable beyond her years. Her comments are always original, and she is so determined and so strong. She has the resilience of someone twice her age. And it doesn't hurt that she is gorgeous, *kh*!

From the unique miracle we had at her birth to the most wonderous journey of amazing therapists, even her progress is simple, original! Only *Hakodesh Baruch Hu* led us to where we are in her journey *BH*.

Did I mention I love the feeling of being original?

She's that and so much more! ●

Rain or Shine

E. Eizikowitz

Sruly, my sweet, clever son, is a charmer with a lighthearted, quirky sense of humor. He is almost four years old and can walk with the support of a walker despite the very tight muscles in his arms and legs and a very weak core. We've explored various forms of therapy, each with varying degrees of effect. He's embarking on a new journey with MEDEK, and we hope this next step in our hishtadlus will bring positive changes.

Sruly was born a few weeks before Pesach. I was excited, grateful, exhausted, and determined to make the most of a few days of relaxation at a *Kimpeturin Heim.* Adding to the stress of a pre-Pesach birth, my mother was sick with COVID-19 and needed extra help. Finding alternative accommodations for my children for a few days was challenging, but we trusted in *Hashem*, and He made it work. Straight after the *bris*, my husband drove me to the *Kimpeturin Heim*, where I entrusted Sruly to the devoted care of the nursery staff. With a sigh, I sank into the plush couch in my room. I so desperately needed this.

Sruly was fussy and cried a little that afternoon, and I thought nothing of it; he did have his *bris* that morning. I slept soundly with Sruly in the nursery for the night, but at six o'clock in the morning, the baby nurse told me he had cried a lot. Though he nursed well, something didn't feel okay; he felt too warm, so I took him back to the nursery and asked someone there to check his temperature.

'One hundred and two degrees.' I gasped, and my heart sank.

Mr. Eizikowitz, I'm surprised you brought all this here. We have the results of Sruly's recent blood tests, and his levels are stable. We're sending you, your baby, and all your boxes home. Right now.

'Do you want to wait for a doctor to see him at nine o'clock, or do you want us to call *Hatzolah* and take him to the hospital?' I took a deep, slow breath and tried to think rationally.

If the nurse suggested *Hatzolah*, I thought, it could be a real emergency. '*Hatzolah*. Please call *Hatzolah*.'

The Emergency Room buzzed like a hive, with doctors, nurses, and technicians swarming around us. Everything happened in a blur; someone took his temperature, pricked his tiny heel for blood, and inserted an IV line into his delicate veins. The most terrifying moment was the lumbar puncture to test his spinal fluids.

I could barely sit still as I waited anxiously for a doctor to explain what was wrong with my baby. Later in the afternoon, as I paced around the hospital crib, Sruly had a seizure. It was terrifying to see his tiny body jerk with each convulsion.

'My baby is having a seizure,' I shouted at a nurse; she quickly called an ER doctor, who administered anti-seizure medications.

Sruly had another, much bigger seizure later that night and was transferred to the PICU. The pace in the PICU was frenetic: an MRI and more blood tests. I was restless, worried, exhausted, and waiting for what felt like forever for some information.

It took two excruciatingly long days to get a diagnosis: viral encephalitis, a type of meningitis. Because the infection was viral, antibiotics would be useless. There was not much to do but *daven* and wait. It was a very long week before Sruly's health began to improve bit by bit, but his tiny veins could not support the IV, which popped out seven times, so the doctors had to insert a central line in his neck. It took another two weeks to see more recovery.

As we got closer to Pesach, I was too afraid to think we might not be home for *Yom Tov*. It seemed to take forever for the infection to clear. My older children were unhappy; what was supposed to be a few days away, and then coming home with their new baby brother had stretched into weeks. We all just wanted to be home. Finally, one afternoon, we were given the all-clear--one more ultrasound, and we could leave. We would all be at home for Pesach, after all.

While we waited for the ultra-sound, I mustered the courage to face the elephant in the room I had been avoiding since Sruly's first seizure. I warily asked the doctor, 'Do you think the infection will affect Sruly's development?'

He studied me and raised an eyebrow. 'Mrs. Eizikowitz, the question is not whether there will be an effect but what the effect will be. Looking at the MRI, we can see there is damage, but there is no way of knowing what is happening now,' he said coolly.

Seeing my panic, he smoothly added, 'We'll know more as he develops and starts walking, talking, and toilet training.'

It was a few days before Pesach, and I had other things to focus on for now. I pushed his indifferent answer out of the way and watched as he removed Sruly's central line and did an ultrasound to check that everything was ok. It was not ok; we were not leaving the hospital yet. I felt like the floor dropped under me and was free-falling. All I wanted was to take my almost healthy baby home and enjoy Pesach with the rest of my family.

A blood clot had developed in Sruly's neck from the central line, and he was given blood thinners twice a day. There was no way to know how long it would take for the clot to dissolve and his blood levels to be stable.

> I'm not getting wet because I've been caught in the rain: Hashem wants me to get wet, so He makes it rain!

On *Erev Yom Tov*, my husband arrived at the hospital with a cart piled high with Pesach essentials. He brought everything: his *Kittel*, *Ke'arah*, *Simanim*, *Haggados*, grape juice, and food for *Yom Tov*.

Right outside the hospital room, he nearly collided with the doctor.

'Mr. Eizikowitz, I'm surprised you brought all this here. We have the results of Sruly's recent blood tests, and his levels are stable. We're sending you, your baby, and all your boxes home. Right now.'

All at once, I went from feeling weighed down and despondent to feeling light, happy, and hopeful; it was dizzying. We were living our own *Yetzias Mitzrayim*!

Time passes fast when you're busy, but eventually, I had to face the inevitable. Sruly was five months old and did not reach developmental milestones. He wasn't babbling, trying to roll over, or reaching for toys. Once again, I had to be courageous and ask painful questions. My baby had to undergo a series of tests, evaluations, and an MRI. We were told Sruly has Spastic Diplegia Cerebral Palsy. I had no idea what the diagnosis meant, but I was determined to maintain a hopeful and positive attitude.

'Don't worry about it,' the doctor reassured us. 'I'm giving you this diagnosis so that you can apply for services and start Sruly on therapy.'

I did worry just a little bit. Ultimately, the diagnosis was not only 'so Sruly can get services.' It shapes a big part of Sruly's life and guides us to the best therapies and services to improve his development.

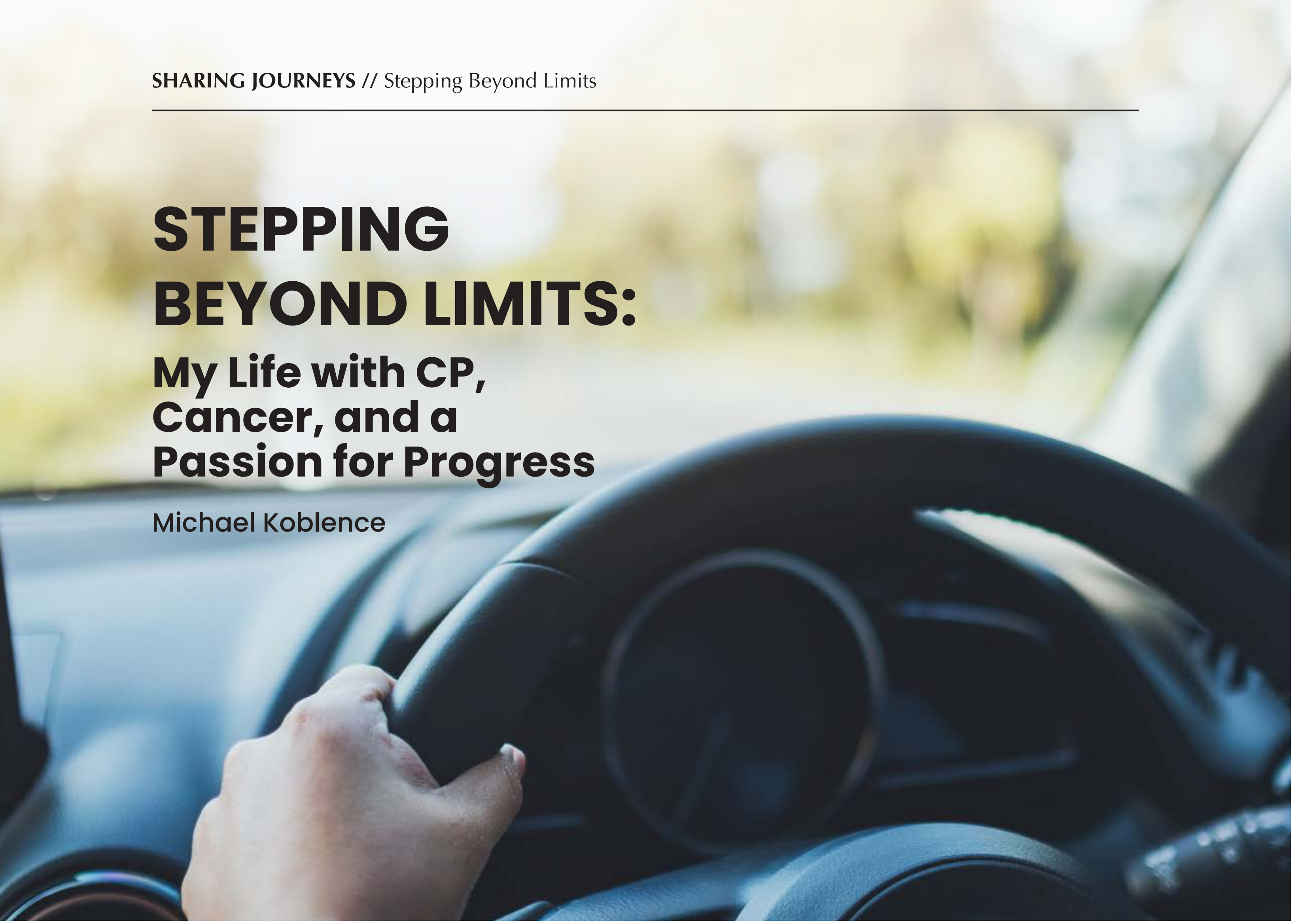
Maintaining a positive outlook and reliance on *Hashem* made accepting my adorable, smiling baby's deficiencies easier. I knew I needed to keep an open mind and heart to do my best for Sruly and my family. I adopted a new mantra, repeating, 'I'm not getting wet because I've been caught in the rain; *Hashem* wants me to get wet, so He makes it rain!'

I was showered with new challenges and had to find new solutions. I insist on a 'positivity project' in my family, and we focus on acknowledging and accepting that everything we have and encounter is custom-tailored for our benefit. Whether it feels 'good' or not, it's all from *Hashem*, the source of only good. *Hashem* determines Sruly's development; we are simply the *shluchim* who do our best for Sruly's progress. This attitude brought tremendous ease into our lives.

At this point, Sruly is doing very well, *Boruch Hashem*. As I mentioned, he can walk with the support of a walker, and his speech is quite good, too. His tight muscles must be stretched daily, and he loves to include his 'mentchies' in his therapy sessions. Despite his ever-growing vocabulary, he sometimes gets stuck on his words and articulation because of poor motor planning. He's a happy little boy who loves to be 'part of everything.'

I've come to terms with his physical limitations but still struggle to understand and advance his social and cognitive challenges. It can be perplexing. Because of his distinct abilities, we divided his school days into different settings. He spends two days a week in a mainstream classroom, which promotes his social development, and he loves being part of the 'regular' children. On other days, he is in a contained, skill-building environment that allows him to improve his focus on tasks and activities.

I count our many blessings and thank *Hashem* for the gifts He keeps showering on us. We are privileged to be Sruly's family; we are so grateful for the experiences and have grown because of him. We are closer to *Hashem* and closer as a family. Sruly is such a loving and happy little boy, an integral part of our family, and we can't imagine life without him. ●



STEPPING BEYOND LIMITS:

My Life with CP, Cancer, and a Passion for Progress

Michael Koblence

I'd like to start by introducing myself because I've recently joined the magazine. My name is Michael Koblence. My parents have always explained to me that the doctor said that I was a miracle baby and that they wanted to give me a name in line with that concept. So naturally, miracle and Michael sound similar! The name Michael in Hebrew literally translates to "gift from G-D".

After having brain trauma, the doctors knew that I was going to have issues that would show up soon afterwards. Because babies are so dependent, it was hard to tell exactly what the issues would be. All they knew was that my cognitive abilities would stay fully intact. As I was not yet walking at the age of three, my parents visited a neurologist, because not being able to walk by that point is considered abnormal. After an examination, I was quickly diagnosed with cerebral palsy. Until today, I have lived a pretty typical life with all the joys and challenges of CP.

In the beginning of 2024, I was able to secure an internship at the New Jersey Office of Homeland Security. This was a pretty big accomplishment for me. I started there at the beginning of June but was forced to stop three weeks into it because of a shocking diagnosis of cancer. I am very excited about the prospect of potentially going back in the summer of 2025. I had really enjoyed my time there and had gotten the opportunity to collaborate on projects about topics that I was really interested in. The diagnosis of cancer was a true shock to me and my family. Sure I have CP, but otherwise, I have always been a very healthy person. I have always made an effort to eat well and workout and have never really had any significant health problems. Cancer was the last thing on my mind as I dove into my packed summer of work and fun. The type of cancer that I had was called embryonal rhabdomyosarcoma, located in the orbit of my left eye. This type of cancer affects around 400 people per year. Once I got over the initial shock of having cancer at 21, I was very grateful to learn that this type of cancer has around a 97% survival rate. After the initial diagnosis, it was just a matter of finding the right doctor and going through the process.

Chemotherapy lasted from mid-July to mid-December, so I just got finished with that. I also had to get radiation on my eye for just over a month and I'm happy to say that I received my scans and I am officially cancer free as of Jan. 2, 2025! Now that I have concluded my entire treatment, I couldn't be more excited to return to my regular life. Not that I hadn't been doing that throughout treatment, as I have made some of my fondest memories during my cancer journey. Cancer has really taught me so many lessons, some of which were to live in the moment and to appreciate what I have, and that the value of a clean bill of health is unquantifiable.

Cancer has really taught me so many lessons, some of which were to live in the moment and to appreciate what I have.

Unfortunately, having cerebral palsy has prevented me from some really cool things in my life. Activities that neurotypical kids enjoy doing like riding roller coasters and jumping into pools were relatively inaccessible to me, especially when I was younger.

My cerebral palsy has taken a dramatic upswing in recent years due to my big efforts at the gym, and I am proud to say that I have recently been able to do some of those cool things that I have never before attempted. Most recently, I rode on most of the roller coasters in Orlando on my trip with Ohr Meir, an awesome organization that takes kids with cancer to Orlando for a few days. I never had a specific fear of rollercoasters nor was there a reason why I couldn't ride on them, but I never really went on them. To be able to say that I went on many of the roller coasters is really exhilarating for me.

One of the cool things that I have done is ridden a helicopter twice when I was younger, once over the Grand Canyon and a second time over the New York City skyline. I still have a lot of progress that I need to make when it comes to swimming. I have always had a fear of deep bodies of water, especially when my head is fully submerged, making it difficult to breathe. I'd love to conquer that fear as well and learn how to swim.

A significant aspect of navigating life with cerebral palsy has been achieving certain personal goals, often centered on reaching the key milestones. These milestones typically revolve around attaining independence. This is something that has always been a priority for me. They remind me that I can if I try.

A big milestone for me was getting my driver's license! I see G-D's hand helping me through my journey. I had wanted it badly for a long time, and my aspiration was compounded by the fact that I was prevented from getting my permit for six months after my 16th birthday. This is when most people in New Jersey typically receive their driver's license. The driving school had refused to allow me to take lessons when I wrote that I had mild cerebral palsy on my permit application. This was one of the only times in my life that I can remember getting that literal pushback due to my disability. Not only did I have to battle with my own confidence in my ability to drive, but I had to now convince someone else as well, without having any experience behind the wheel. In the end, I overcame that pushback and with a lot of determination, passed my driving test on the first try! It was a moment that felt like a true accomplishment. Another milestone had been met. I've been driving for over three years now and have thoroughly enjoyed it!

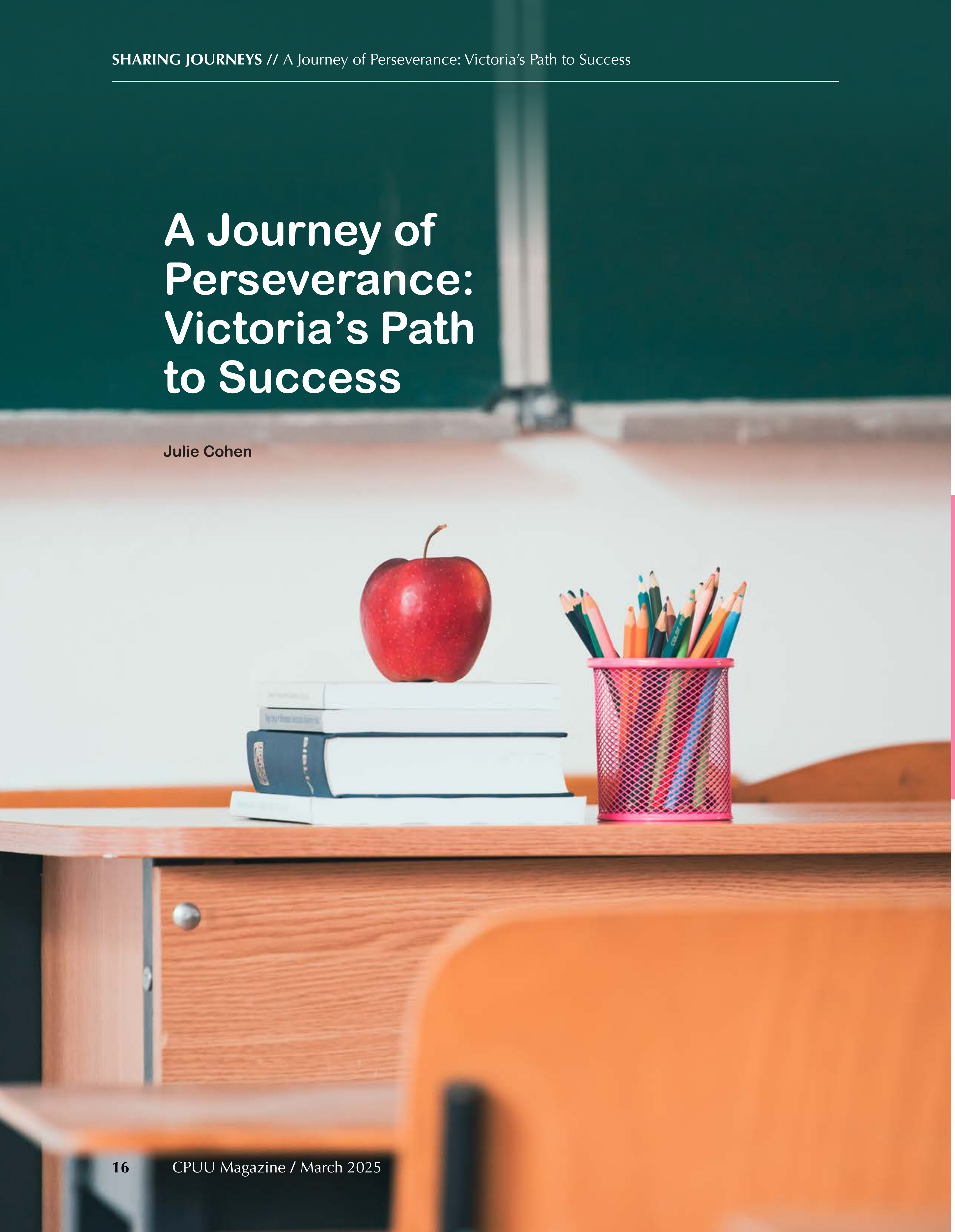
Cerebral palsy has been and will always be a big part of my life and who I am as a person. Like most individuals who have it, I cannot really imagine life without it. I will always have to deal with the inconsistencies of movement that come with it. Trust me, I have gotten plenty of funny comments about my walking. People sometimes ask me how much I have had to drink that night when they observe my movements. This is a weird consequence of having cerebral palsy. However, with G-D's help I hope to continue to improve over the years. The great thing about cerebral palsy is that it is not progressive, meaning that it only improves the farther you get from the incident. Cerebral palsy has not and will not prevent me from living a normal, happy, healthy and productive life. I could not be more excited for the future!

I would like to say that I am super grateful for the opportunity to write in the magazine! It allowed me to put some thoughts on paper that I didn't even know I had. I hope to have the opportunity to write for it again! ●

Michael Koblence is a 21 year old passionate creator who shares his life with cerebral palsy and his recent cancer journey. He inspires others by overcoming challenges and pursuing his goals. Despite the obstacles, Michael remains determined to live life to the fullest, recently conquering roller coasters and a fire walk. He is excited for the future, with plans to continue sharing his journey and breaking barriers along the way.

A Journey of Perseverance: Victoria's Path to Success

Julie Cohen



In the heart of Brooklyn's Syrian Sephardic community, amidst the vibrant streets of Flatbush, my daughter Victoria's journey has been one of resilience, determination, and unwavering faith. As the fourth of my nine children, Victoria has defied expectations and rewritten the script of what was once thought impossible. Now, at 22 years old, she continues to inspire those around her with her unyielding spirit.

A Loving Beginning

Victoria's educational path began in an unexpected place—Eis Laasois, a preschool that welcomed her with warmth and open arms despite our different backgrounds. The school was a place of comfort, where the air was always filled with the scent of something delicious cooking. From the ages of two-and-a-half to five, Victoria thrived in an environment that celebrated her.

> Placing a Syrian *Sephardic* girl into an *Ashkenaz* school would make it even more challenging. I was hurt but *Hashem* had a different plan for me.

But as she grew, new challenges arose. Because Victoria was non-ambulatory, local *yeshivas* were unwilling to accept her. With guidance from our community rabbis, we enrolled her in a public school that provided essential on-site therapies. Despite the unfamiliar setting, as we were far from *Yiddish*-speakers as possible, the bilingual *Yiddish* program became her world, thanks to the dedication of an extraordinary educator, Enid Smith, who treated every child as her own.

Navigating Public School

By the time Victoria reached fifth grade, her heart yearned for more. Her *neshama* was bursting. She longed to be among *frum* Jewish girls, to wear a uniform like her sisters who attended Beit Yaakov. Determined to nurture her *ruchnius* spirit, I bought her the button-down shirt and skirt she so deeply desired. It was a simple act, but it symbolized her belonging.

When I voiced my hopes to the principal of my older girls in Ateret Torah, of finding a *Hebrew* school for Victoria, I encountered skepticism. "Why would a school take her if she doesn't know *Hebrew*?" she asked. It had never occurred to me that Beit Yaakov wouldn't take her.

That moment sparked the next chapter of Victoria's journey. I created a classroom within our home, assembling a team of teachers to immerse her in *Torah* studies, *Hebrew* reading, *Chumash*, *Navi*, and *Yahadut*. For two years, my house transformed into a school, so besides the hat of a mother, therapist and wife, I took on the role of principal, ensuring she had access to the education she deserved.

To celebrate her progress, we held a *Siddur* party one just like every other young girl receives. Her teacher laminated her first *Siddur* to protect it from her drooling, and we invited family members to rejoice in this milestone. Victoria's journey was different, but it was filled with the same love and joy as her peers.

Breaking Barriers in School

As Victoria approached upper-elementary school, finding the right fit was an uphill battle. I looked at more than 20 educational programs, at special ed schools and regular ed schools. I went to New York, New Jersey, Staten Island, Long Island and Queens. Over 20 schools turned us away. One *Ashkenazi* principal suggested we look within our own Syrian community, as she would stand out too much in an unfamiliar setting. She was already sticking out, being differently-abled. Placing a Syrian *Sephardic* girl into an *Ashkenaz* school would make it even more challenging. I was hurt but *Hashem* had a different plan for me. I just had to hang in there to watch and wait for it to reveal itself.

In the end, the perfect answer was in our own backyard—Orot Sarah, a small Beit Yaakov school that welcomed Victoria with open arms. Thanks to her *Hebrew* tutoring, she met the school's requirements, and the staff embraced her as a privilege, not a burden.

The administration did not know how to evaluate her and what grade to place her in, so they just pretty much looked at her size and said, "Okay go to third grade." In her first year of Orot Sarah year she celebrated her *bat mitzvah* and after that quickly advanced to sixth. Though her classroom was on the fourth floor of a non-accessible building she refused to let obstacles define her. Victoria climbed the stairs daily, down for lunch, up for recess and then back down again. As many times as her classmates went up and down, she did too, never once asking to be carried, proving that her will was stronger than any limitation.

By twelfth grade, Victoria was nearly 20 years old, and she took immense pride in being the eldest in her class. She was not just accepted—she was cherished, becoming a beloved member of the school community.

A Life Filled with Learning and Growth

Beyond formal education, Victoria's life was filled with therapy sessions—up to 18 per week, from the time she came home from the hospital. Our home became a revolving door of therapists—OTs, PTs, speech therapists, and special educators—many of whom became like family.

I quickly learned that advocacy was crucial. At one point we needed more hours of early intervention, I remember calling and calling and leaving countless messages to secure the services she needed. One Friday afternoon, after weeks of trying, I thought "Wow the house is so quiet. Let me try calling now." A supervisor finally answered I said, "Hi, my name is Julie Cohen--" and she finished my sentence, "Mother of Victoria. You can have all the services you need, because you just didn't give up." That was the precursor to those 18 sessions a week, the maximum allowed at that point in time. That relentless persistence ensured Victoria received every available resource.

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> I said, "Hi, my name is Julie Cohen--" and she finished my sentence, "Mother of Victoria. You can have all the services you need, because you just didn't give up."

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Faith and Miracles Along the Way

Victoria's journey has been filled with moments of *siyata dishmaya*. The very school that welcomed her, Orot Sarah, closed the year she graduated. It had been there just long enough to serve her needs. When her wheelchair was stolen outside a Jewish children's library, a manufacturer in California expedited a replacement, cutting paperwork so that we would have the chair in time, understanding the urgency of the situation. Time and again, we saw *Hashem's* hand guiding us through the unknown.

Keeping a log of these moments of *Hashgacha Pratit* became a source of strength. *Hashem* gave her to me, to my husband, and to my children and so therefore he's going to give me the tools I need to raise her. Every challenge comes with a solution, reinforcing our faith that we were never alone.

The Present and Beyond

Today, Victoria continues to learn and grow from home. I have recreated the model of a school within our house once again. She studies *Biur Tefillah* and *Tehillim*, and she receives OT, PT, and speech therapy regularly. She also works a few hours a week at a local *yeshiva* library, remaining engaged and active in our community.

A Message of Hope

For mothers walking a similar path, I offer this message: never stop believing. When Victoria was in the NICU, doctors painted a bleak future. They told me she would be blind, deaf, unable to walk, talk, or eat. And yet, here she is—22 years old, seeing, hearing, speaking, walking, and eating. Our *tefillot* were answered.

Children like Victoria are a gift. They teach us patience, faith, and perseverance. I have learned that when we ask for help and open our eyes to the blessings before us, we find the strength to navigate even the toughest journeys. Victoria's path was never easy, but it has been filled with love, triumphs, and the unwavering belief that with *Hashem's* guidance, anything is possible. ●

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Going To a Wedding with CP Is Fun!

C.Y.C.

Tonight is my friend's wedding, and I want to enjoy it. What can be more fun than getting dressed up and doing my hair and makeup? It's fun to be a girl, isn't it? However, challenges often come up. At times, when I do my makeup and I look in the mirror, I can't help but see myself looking as if I had a 4-year-old makeup artist who painted my face. My hands make little involuntary movements that are totally not welcome at this moment in time, but they didn't ask permission to come. I want to look good and presentable, like everyone else my age. There are numerous people that I will see at this wedding, and I will attract a lot of looks as I sit in my wheelchair.

I try to eat before I leave for the night, but that plan doesn't work out. I try to get ready before my friends come to pick me up, however there isn't enough time. Although wedding food looks great, I know that I will not be able to eat any of it. If I were to try, it might not be a pretty sight, as I usually need help eating. I am certainly not going to ask my friend to feed me in front of everyone, especially not in a public setting. I suppose I will have to eat when I get back home.

The music is fun, and it looks like the crowd is having a blast on the dance floor. I am genuinely happy for my friend, but at times it's hard to feel a surge of joy for my friend who is glowing in a stunning white gown when I'm sitting in a wheelchair. I can't move around the dance floor easily like the rest of my friend. I wonder to myself, 'Will this always be my reality?' I try to get up and join the dancing circle, but it slows everyone else down, so I end up going back to my wheelchair and watching. A few minutes later, I make my way to the middle to get to my friend the *kallah*, and the crowd goes wild.

People come over to talk to me, friends, old teachers from school and others from around the community. These are people who know me, but I don't always recognize them. I nod and smile to be polite and I think to myself that I have so much to say but my mouth is closed. If I even try to speak slowly, the music is still too loud, which makes it even harder for anyone to hear and understand me. Instead, I just smile, nod, and stay quiet. At least I can look pretty while doing it!

Lately, weddings are the only time I get to see my friends, and I would so love to chat and catch up on life like any other adult. However, with booming loud music it's almost impossible! I'm much too embarrassed to bring out my iPad to communicate, even though that's how I talk when I'm out of the house. Sometimes it feels like people outside are just trying to make me feel good, like I'm some kind of *chesed* case. My friends at the wedding offer me a ride home, but I politely decline because I can't ask them to lift my wheelchair in and out of the car, while they're all dressed up and in heels. It's too much to ask.

I really want to enjoy this moment for my friend, but sometimes, it's hard not to feel like I'm an outsider looking in.

The Same Mother

Ayala Rosen

I awoke with the dreadful realization that it was Monday. The thought sat heavily on my limbs, pinning them down to the bed like dead weights. Tzippy's screams from last week had scarcely ceased to haunt my dreams and here it was Monday again.

It was 7:30 already. Marilyn, the physical therapist, would not extend the session if we come late, and we paid a steep price for every minute. I dragged myself out of bed.

"Come, Tzippy. Give me your right hand," I cajoled, holding the pretty printed blouse aloft. My daughter lay face-down, reddish hair strewn across her pillow. Her arms were locked tightly at her sides. If only she would use some of that iron resistance against the spasticity that gripped her legs, I thought sadly. Maybe then we could start making headway at the therapy sessions.

Somehow, I wrestled the outfit onto Tzippy's stiff frame. I pulled my daughter to a sitting position and whipped out the brush. My fingers deftly braided the soft auburn locks. I tied two ribbons in her gleaming braids. "Now you can look in the mirror, Tzippy!" I announced jovially.

Tzippy turned to face me for the first time that morning.

I saw my daughter's wet, splotchy face and my heart sank. Tzippy must have been up for a long time, crying into her pillow. "I don't want to look in the mirror," she sulked. "I'm not going to school anyway, just to Marilyn the witch."

I sighed. I hoisted my eight-year-old girl into my arms and carried her down the stairs. "Let's eat breakfast, Tzippy," I sat my daughter down at the table. My words sounded halfhearted to my own ears. Tzippy never touched breakfast on Mondays. She barely spared a glance for the bowl of steaming oatmeal I had lovingly prepared.

We sat in the car service in silence. I pulled Tzippy close and put my arm around the stiff shoulders. I could feel the tension rippling through her frail body. Poor, sweet child.

"Mommy, do you remember the exercises I showed you last time?" Marilyn's voice sounded strident in my ears.

"Yes, I think I do."

"Good. Let us start, then." Tzippy lay stiffly on the table. She began to howl before Marilyn even touched her. "No, no, it hurts!"

Marilyn, impervious, grasped Tzippy's leg and began to massage it. She motioned for me to do the same for the other leg. Tzippy shrieked for all she was worth, until her voice turned ragged and she could barely get out a hoarse scream. I blocked it out. I concentrated fiercely on the task at hand, on pulling, pushing and massaging the unresponding leg as gently but persistently as I could.

Marilyn tested Tzippy's reflexes when they were done. She nodded in satisfaction. "She's doing so much better."

She patted Tzippy on the arm. "Soon you'll be taking steps, my dear, and before you blink, we'll have you running races!" Tzippy glowered at me.

"Thank you so, so much, Marilyn," I gushed. The happiness bubbled in my heart. This was the most positive report I'd received from the therapist in a long time. Apparently, Marilyn's insistence that I learn the massages and apply them throughout the week had born fruit.

"Have a good day," Marilyn smiled graciously. "See you next week, Tzippy." Tzippy shot daggers from her flashing blue eyes. She didn't deign to respond.

I sat her in the wheelchair. "Did you hear, Tzippy?" I chatted happily as I opened the heavy glass door of the rehab center. I nodded gratefully as the secretary rushed to hold it open for me. "Marilyn says you'll be walking soon!"

Tzippy turned icy eyes on me. "She hurt me!" She choked back a sob. "And so did you," she whispered, staring straight ahead.

I stopped short. Had I heard right? "What, Tzippy?" I uttered faintly. She shrugged angrily. A grey car pulled up to the curb and its bearded driver rolled down the window. "You called a car?"

I nodded. As I lifted Tzippy out of the wheelchair, she resisted tenaciously. I felt tears coming. "Tzippy, let's get you into the car, okay?"

The driver was a nice one. He got out, folded the wheelchair as per my instructions and hoisted it into the trunk. "Thank you," I sighed in relief. "I so much appreciate it."

I attempted to put my arm around Tzippy's shoulders again, but she pulled away. She huddled against the car window and refused to look at me.

"Where are we going?" the driver wanted to know.

I was about to say my address the way I did every week. Somehow, different words emerged. "The Ice Cream House, please," I requested, "And then another stop at Prospect Park."

"So, what will we have, Tzippy?" I asked heartily. We were in the ice cream store, a child's dream. I parked the wheelchair close to one of the screens where we would put in our order. I checked that Tzippy's hands could reach the screen. "Come, you want to put in our order, sweetie?"

> "I thought maybe when we go to the therapist, a different person comes that looks like you, Mommy," Tzippy haltingly continued. "Because she's so mean, even when I cry, she doesn't stop and doesn't even care!"

Tzippy looked at me. Her blue eyes were wide with wonder. "You let, Mommy?" I nodded. Tzippy smiled cautiously for the first time that day, and I felt my own tight muscles relax, even as I considered which neighbor to call to take the kids off the bus.

Half an hour and much hustling later, we sat together on the grass, bathed in the warm sunshine that filtered through the treetop above.

Tzippy licked her double cone. I watched her, smiling. "Is it yummy, Tzippy?" She nodded blissfully.

"Tzippy?" I wasn't sure what to say, but I had to ask the question. "*Zeeskeit*, were you angry at Mommy earlier?"

Tzippy went rigid. "N-no," she said, eyes darting. "I mean, I don't know."

I moved closer. "You know the therapy is for your own good, right?" Dovid and I had repeated this so many times to Tzippy.

Tzippy's forehead furrowed. "I don't know, I just thought…" She played with her ice cream drink, sloshing the straw around and around. I waited.

Tzippy licked her cone quickly. She stared at her cone while licking it, as if it would disappear if she removed her gaze from it. "Mommy, are you the same?" she finally blurted.

"What?" I set down my drink and came very close to Tzippy. "What did you say, Tzippy?"

"I thought maybe a different Mommy came." A deep blush colored Tzippy's clear skin. "I thought… someone else came that looked just like you," she peeked at me. "When we were in Marilyn's room," she explained.

"What?!" I couldn't seem to get any other syllable out of my mouth.

"I thought maybe when we go to the therapist, a different person comes that looks like you, Mommy," Tzippy haltingly continued. "Because she's so mean, even when I cry, she doesn't stop and doesn't even care!" The last words came out as a sob.

"You mean, this other Mommy?" I asked softly. Tzippy nodded.

I hugged her close. "You know that makes no sense, Tzippy," I spoke softly. "You only have one Mommy and she doesn't change."

Tzippy finally sank into my arms, leaning her head on my shoulder.

"Even when you cry," I stroked her hair, "And it seems that I don't listen…" I breathed deeply. How to explain?

"Do you want to walk like everyone else, Tzippy?" The auburn head nodded emphatically into my shoulder.

"I want it too," I said simply. "I want my Tzippy to walk again. So, even when you scream, I continue to do the massages because I know it helps. I don't stop because then how will we help you be able to walk?"

I slid Tzippy back onto the grass and cupped my chin in one hand. "But that's why we go buy ice cream afterwards, because I also want you to be happy!"

Tzippy was silent the whole way home. This time the silence was a comfortable, thoughtful one. I observed the passing trees and houses through the window.

"Who would have thought," I mused, that my daughter had gotten such an outlandish idea into her mind! But then, that was her way of making sense of the conundrum she encountered every week, the perplexing contrast of her loving mother who wouldn't stop hurting her even as she shrieked in pain.

Perhaps Tzippy would only fully understand, I realized, once she began to walk. Then she would see the purpose in all the suffering. Until then, I hoped Tzippy would trust me that I was always the same, loving mother in the therapy room and in the ice cream store.

"But how can it be?" Sometimes it's so hard to understand.

"If *Hashem* loves me so much, why am I still waiting for a *yeshuah*? Why am I or my daughter still suffering?"

It's a question that sometimes inches its way into our hearts.

Purim comes and frees us from all the questions. The same loving Father that saved us by putting *Esther Hamalka* into the palace of Achashverosh, is also the One Who caused us to suffer from Haman's deadly decree.

All for our own good. All, in order to cleanse our neshamos so that we become worthy recipients of *Hashem's* most wonderous miracles.

The same Father Who continually showers us with blessings, is the same One who sometimes must make us go through hardships. All for our good and all with the same love. ●

Adapted with Permission from The King David Center Senior Times

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REAL QUESTIONS *REAL ANSWERS*

Shoshana Levin (Zyman), OTR/L

Q I heard about vibrating boards. Can you please explain the benefits and ins and outs of vibrating boards and how they work? Would you recommend it to be used at home? Why?

A Thank you for the question! Vibration boards or platforms are a great tool which can be extremely beneficial for children experiencing weakness, abnormal tone, spasticity, or sensory issues. I use them frequently in sessions to achieve different outcomes, depending on the child. First of all, for those who have never heard of or seen a vibration board, it is what it sounds like: a rectangular platform which vibrates horizontally, vertically, and/or oscillates (alternates) with various speeds and settings. Utilizing vibration during treatment is a widely researched and useful technique that many clinicians, including OTs, PTs, and SLPs, will incorporate as a preparatory activity or in conjunction with active movement. It works to target many problem areas.

Individuals who experience muscle weakness often lack the strength to utilize specific muscle groups in order to accomplish functional tasks. For example, a child with hemiparesis (weakness on one side of the body) may have decreased strength in one hand, which can impact dressing and other bilateral activities of daily living. Using vibration before or during an activity can help recruit muscles by firing up motor neurons. Muscle recruitment is an important factor in accomplishing tasks, as it allows the joints and body parts to move in a smooth and coordinated way. This assists in allowing children with weakened muscles to complete everyday tasks.

Vibration can be especially useful to reduce spasticity. CP often presents as abnormal or increased tone and spasticity in any number of locations in the body. Vibration can work to counter the effects of high tone by "shaking" up the muscles, thereby loosening the area for short periods of time. When tone is reduced, the appropriate musculature can better be utilized to complete a desired task. This is due to the reduction of stiffness that may block muscles from functioning optimally. When a child with stiffness in the upper extremity or shoulder girdle utilizes a vibration platform in the weight bearing position, it helps to activate extensor muscles in the neck, shoulders and hands, and inhibit excessive flexion. Alternatively, in a child with excessive low tone, vibration can help to recruit muscles and contract them for active movement. They can also be used to help maintain various positions such as sitting, crawling, or standing. The vibration board is most effective at reducing spasticity when combined with active movement. However, when a child is merely sitting passively on the vibration board without activating muscles, it will be less effective. In general, any vibratory tool should be used in conjunction with active movement, such as working on feeding following an oral massage with a z-vibe, etc.

Many individuals with cerebral palsy also experience sensory processing issues, due to their abnormal neuro-motor development. Vibration is a great way to increase body awareness (proprioception), the feeling of where we are in space (vestibular awareness), and improve overall regulation. It may up or down regulate a child, so depending on its response in your child, you may not want to use it before bed or you may want to specifically use it when your child seems out of it or under-responsive. If your child starts getting dizzy while on the vibration platform, turn it off. You may need to adjust the settings, speed, or amount of time you are using it, depending on your child's sensory tolerance.

While I highly recommend vibration in therapy and for home usage, there are a few things to keep in mind. Vibration platforms are not a cheap investment (the cheapest ones are around $150), so first ensure that your child responds well to it and that you will be able to implement it into your home routine before you buy. If you decide to try a cheaper option first, opt for a handheld vibration tool, which can be used on specific muscle groups. Some options include a battery-operated handheld back massager, a sensi or z-vibe for oral motor skills or awareness, or even an electric vibrating toothbrush to start with.

There are some contraindications for vibration boards as well. Children with cochlear implants are contraindicated for full body vibration usage. Consult with your neurologist if your child has a shunt, to confirm that it can safely be used. Additionally, children with auditory defensiveness may have a hard time acclimating to the vibration board, as it does make a noise. Ask your therapist if he or she recommends their use for your child and make sure there are no adverse responses noted during sessions. Monitor your child during and following vibration board usage, and take note of any positive or negative effects which should then be discussed with your therapists.

Good luck!

Shoshana Levin (Zyman), OTR/L ●

Do you have a question for Shoshana?
Email: cpuumagazine@gmail.com or
Call: 347-920-0771

Abandonment- Don't Let It Happen

Ronit Finkelstein, M.S. CCC-SLP ATP

Abandonment in AAC (Augmentative and Alternative Communication) refers to starting and then deciding to stop using a device. Abandonment usually leads to rejection. Rejection means refusing to use the device altogether, even if the user risks losing an effective means of communication.

Rejection or abandonment happens gradually. Knowing the signs or symptoms indicating rejection is essential to ensure that rejection and/or abandonment do not occur.

- **Ease of Use:** As discussed in previous articles, every AAC device and program has unique features and methods. Choosing the best device/method for the user and their family is vital. Consider the following: the user's vocabulary, the family's ability to program, whether they are comfortable using the device, and home schedules and routines.
- **Support and Training:** If the speech therapist does not have experience or knowledge in AAC or a specific device, it will usually lead to confusion and frustration. Communication works as a two-way street. The family and the user need appropriate training to increase motivation and promote better communication. Without family support and interaction, the user will lose opportunities to practice with the device.
- **Device Portability:** The device must be easy to move from one place to another. A user who wants to be independent needs a portable device.
- **Negative Attitude:** A negative attitude can come from family members, caregivers, or the user. There might be embarrassment regarding the use of a device or negative feelings from a poor experience in the past.
- **Maintenance:** Vocabulary increases as a child develops, and interests and hobbies change over time. The user will want to use a device with his words and expressions incorporated. Update and program all new words, terms, and slang along with the user's development.

The following tips can help to decrease the chance of abandonment and rejection of any device, old or new.

- Present choices and provide opportunities for the family and support staff, and if possible, the user, to work together and establish realistic goals and expectations. Learning to use a device is like learning a new language; it takes time, patience, and practice. Try different apps before settling on one, and include the family in the process to ensure the best fit for the user.
- Provide hands-on training, frequent coaching, and functional experience. Include meaningful vocabulary and incorporate the device into existing routines to encourage use. Using the device should be a positive experience, not perceived as a chore or an assignment.
- Everyone in the user's environment should understand that the device is not just for school or speech therapy. It should be used daily in family conversations to expand the user's community integration.
- Update vocabulary as the user's vocabulary increases and add words that change with the user's environment and interests.

The goal is for the AAC user to take full responsibility for their device, bringing it with them or asking for it wherever they go and ensuring it is fully charged and updated. Sometimes, users take ownership so strongly that they do not want anyone touching their device. It is always a good idea to ask permission to touch or repair something on their device. If necessary, include the user in the process and use screenshots or paper copies to demonstrate what will be changed. ●

> Let's make abandonment a distant memory.

Cerebral Insight

Understanding visual needs in cerebral palsy is greater today, thanks to advanced eye testing

Mind-Eye Institute at Forefront of Latest Optometric Science

Deborah Zelinsky, OD

Children with cerebral palsy may struggle with visual impairments that contribute to developmental delays and learning challenges, especially in the classroom. Unfortunately, many typical eye examinations fail to fully address some of the underlying visual problems these children face. Visual issues encompass much more than seeing clearly.

The list of potential eye disorders in cerebral palsy is large. Blurred vision; an inability to focus on details; loss of visual field, including peripheral eyesight; and oculomotor issues like crossed eyes and involuntary eye movements – eye jerks or turns inward, outward, or downward -- are all products of this muscle disorder. Most of these problems are common and readily detected during a routine eye evaluation.

However, people are not typically tested on their ability to quickly and accurately shift attention from place to place when sitting as compared to when rolling in a wheelchair. This important skill is used in daily life and oftentimes is missed during eye evaluations which aren't necessarily assessing the child's awareness of his or her surrounding environment.

Also untested is the synchronization of sensory systems, specifically coordination of eyesight and hearing. Although the conventional eye examination is sufficient for the general population, people with cerebral palsy need an expanded assessment.

Cerebral palsy results in abnormal brain development from damage to the brain during its development in utero. It is a neurological disorder that manifests in muscle weakness, spasticity and lack of muscle coordination. These difficulties disrupt walking, balance, and other movement activities. Not only are large muscle groups affected, such as the muscles controlling arms and legs, but smaller muscles as well, including those that manage fingers, tongue (speech), and eyeballs.

Typical eye testing blocks off much of a person's peripheral awareness to check the clarity of central eyesight. Central attention represents only about 6 percent of a person's visual awareness. The remaining 94 percent – the peripheral where attention is not selected – governs a person's overall awareness of the surrounding world. When signals from that surrounding world are disrupted, overall awareness shrinks. This governs reflexive action and emotions.

So why may a child with cerebral palsy face such daunting learning challenges?

The difficulties are not with their thinking brains, which are usually operating at normal or above- normal levels. Instead, learning problems are usually based on inaccuracies and slowness of eye muscle movement, which oftentimes leads to some distortion of peripheral eyesight, and the potential lack of synchronization of perceived space through eyes and ears.

Visual and auditory systems must be combined to achieve efficient school performance. Thankfully, 21st century optometric science has advanced exponentially, and optometrists now have the knowledge and capabilities to address wider issues as they relate to the child with cerebral palsy.

We now know, for example, that communication in the brain is often disrupted in neurological disorders like cerebral palsy. And this disruption can disturb the integration of neurons with other body sensors involving touch, pressure, and movement. Specifically, mechanosensory neurons (proprioceptors) found within muscles, ligaments, tendons, and joints transmit information to the central nervous system and, in turn, activate feedback loops. These feedback loops allow the body to move without conscious attention. At the same time, they communicate with other sensory systems, including the ears and eyes. The integrated function and coordination of these neurons are what stabilize posture and prompt body movement, helping with balance and core posture control.

The Mind-Eye Institute (www.mindeye.com), founded more than 30 years ago and based in Northbrook, Illinois, has been studying the role of the eye's retina in neurological health and disease. The retina is composed of brain tissue, sending filtered signals through the optic nerve. Those signals are critical in integrating various sensory maps, including eye-ear coordination, to process visual space and achieve proper spatial awareness. This synchronization of perceived auditory and visual space with proprioceptors optimizes performance. For instance, picking up objects is an action requiring subconscious planning of the amount of energy to exert. If the eyes send signals indicating something is going to be heavy, a person readies his or her arms to lift in a manner much different than when anticipating picking up a small box of feathers. Such optimization, however, is often lacking in patients with cerebral palsy.

> Standard eye evaluations often fail to determine the level of awareness that the typical child with cerebral palsy has when trying to learn and respond to the surrounding environment.

Visual processing involves a complex network of communication signals between the central nervous system (which includes the retina, brain, and spinal cord) and other circuitry, including the emotional, motor, and sensory systems and thinking processes. In children with cerebral palsy, internal visualization is usually not a problem, but external environmental awareness certainly can be.

In evaluating the cerebral palsy patient, the Mind-Eye Institute team applies unique, comprehensive testing that goes far beyond traditional evaluation methods. Tests determine how right and left visual circuits function in tandem while a person is stationary as well as moving. Observations and measurements show how well the patients' attention shifts and readjusts in response to environmental stimuli and assesses the coordination of seeing and listening.

One of those tests, the Z-Bell Test^{SM}, developed and patented by the Mind-Eye Institute, is now internationally recognized as a simple, but revolutionary method of evaluating a patient's overall integration of retinal processing with awareness of auditory space – basically, the stability of the eye-ear connection. During the test,

LEARNING CHALLENGES

In the classroom, a child is constantly shifting attention – from the teacher to the board to the writing tablet, notebook, or book on his or her desk. As the teacher is speaking, the child must listen carefully and retain and comprehend what is said, while taking notes, glancing at the classroom board for additional information, and tuning out distractions. This is not an easy, automatic process for any person, because it requires well developed neurological and sensory skills. But for children with cerebral palsy, the abnormal oculomotor movements and sensory incompatibility of their disorder can make learning an exhausting task. Customized eyeglasses can alleviate some of that effort.

a patient reaches out, with eyes closed, and tries touching a ringing bell. If the patient cannot do so, a Mind-Eye optometrist determines the optimal combination of lenses to place in front of the patient's closed eyelids allowing the patient to find the bell immediately without conscious effort. Light still passes through the eyelids and activates parts of the brain not used for eyesight. With eyes closed, patients must visualize surrounding space to locate the bell. Auditory localization and visual localization must match to lessen overall effort and sensory confusion.

With the Z-Bell Test℠, Mind-Eye optometrists determine whether the environment is understandable or plain confusing for each patient. Changing light dispersion on the retina by using the proper mix of filter, lens, and/or prism, they can then readjust a patient's spatial awareness, body control, balance and selective attention to sounds. The test has changed the lives of both pediatric and adult patients by allowing the Mind-Eye team to prescribe highly individualized, therapeutic "brain" glasses -- Brainwear® technology -- that normalize the balance between central and peripheral receptors in the retina, while improving the synchronization of sensory systems such as vestibular, visual and auditory signaling.

A person's sensory systems are like musicians in an orchestra. Each musician may be highly skilled in a specific instrument, but without a conductor synchronizing what they are playing, the result is simply noise – not music. Cerebral palsy (along with other injuries) can disrupt sensory circuitry and mapping of space. When either central or peripheral eyesight fail to interact appropriately and/or inputs from eyes and ears are out of synchronization, patients often become confused about their environment. This confusion can create a narrowed perception and awareness of surroundings, inappropriate reactions and responses, and difficulties with learning and memory.

Cerebral palsy requires more than improvement of a child's visual acuity, attention to specific objects in his or her central eyesight, and correction of one or more oculomotor disorders. It is a much more complex neurological disorder requiring all the skill and technological capability available. At the same time, the diagnosis of spasticity does not have to be a permanent block to a patient living a quality life.

Advanced optometric rehabilitation offered at the Mind-Eye Institute can help reduce environmental confusion in a cerebral palsy patient's external world. Contact the Institute at 847-501-2020 for more information. ●

Deborah Zelinsky, OD
Founder and Executive Research Director, Mind-Eye Institute

Introduction to Adaptive Equipment for Children with Cerebral Palsy:

A Beginner's Guide for Parents

Shaindy Silber, PT, DPT
Sushi Zucker, MSPT

As a parent of a child with cerebral palsy (CP), you are likely already involved in the many ways you can help support your child's unique needs. One of the most important aspects to explore is the use of adaptive equipment, which can significantly enhance your child's independence, mobility, communication, and overall quality of life. It can even just serve as a comfortable place for your child to rest or be positioned during 'down time' to maximize optimal alignment and allow your child to more easily participate in play and in family activities. This article serves as the first in a multi-part series designed to introduce and explain various types of adaptive equipment, starting with standers, adaptive chairs, head supports and communication devices.

What Is Adaptive Equipment?

Adaptive equipment refers to tools or devices designed to assist children with physical, developmental, or other challenges. These devices allow children to perform activities that they may otherwise have difficulty with, offering greater independence, comfort, and inclusion in family and community activities.

STANDER SYSTEMS: STANDING DEVICES FOR IMPROVED HEALTH AND FUNCTION

Stander systems are devices that help children stand upright. These devices allow children to experience the benefits of standing, such as improved bone density, muscle strength, and circulation. In addition, standing helps with posture and digestion and may have positive effects on spasticity and joint health. (See the article from last issue, "Hip Hip Hurray!" for more info on this). It also places them in an upright position similar to their peers and siblings, often allowing them to be on the same eye level, which is important socially.

Standers are frames that allow a portion of a child's body weight to be placed through their upper body and legs via an upright board or firm cushions. Accessories can be added to assist in maintaining straight hips, knees and upper body, allowing children to take weight through their feet in a standing position. An attached tray table is available so that toys and books etc. can be played with.

There are two main types of standers:

Supine Standers: In supine standers, children are positioned with the supporting board or cushion behind them. The most important distinction is that supine standers provide support behind the head. Most supine standers have the ability to slowly incline as we work towards a fully upright posture. Therefore, this position is often used for children who may not have the control needed for a prone stander but still benefit from the ability to stand.

Prone Standers: In prone standers, your child is positioned face forward, with the support in front of them, under their stomach and in front of their legs. This position encourages head and trunk control and can help develop strength and stability in the lower body. The main prerequisite for this stander is head control. If the child is unable to support their head the supine stander would be the more appropriate choice. These have an adjustable tilt as well.

Standers to accommodate contractures: Most standers position the hips and knees straight, with the heels down. Not all children have the amount of movement of their joints to tolerate this. Some standers are more adjustable and can accommodate other joint positions and are made to distribute the force through the joints appropriately. Your therapist can help you identify which stander companies have this feature.

Mobile Standers: These standers typically have 2 large oversized wheels that the child can easily reach and use to move around their environment (in school for example) while maintaining a standing position. This type of stander cannot be tilted forward or back and often has less support and is therefore appropriate for children who have the ability to propel the wheels and stand with less support.

Sit to Stand Stander: These standers begin as a chair and straighten to an upright position eliminating the need to transfer your child out of the device. This is especially helpful with larger or older children or to help with activities of daily living, such as standing up to reach for items on a table.

It's important to know that standers are adjustable and customizable to your child, and physical therapists can help assess which is the best choice for your child based on their needs. They can also determine which accessories may be needed and can help you adjust the stander so that your child stands in optimal alignment. (Some examples include lateral supports, hip guides, chest harness, adductor pummels, adjustable footplates, and more!)

ADAPTIVE CHAIRS: PROVIDING SUPPORT AND COMFORT

Adaptive chairs are designed to provide children with the support that they need to sit comfortably and safely throughout the day. These chairs are especially useful for children with limited postural control, providing the necessary alignment for daily activities such as eating, learning, playing or just hanging out with the family.

Some popular adaptive chairs include:

Rifton Activity Chair: This chair is just one example of an adjustable adaptive chair. It is widely used by children with cerebral palsy due to its adjustable components and versatility. It offers head support, trunk support, and footrests, making it ideal for children who need assistance maintaining a proper seating position. It also allows for easy transitions between sitting, reclining, tilting and has a vast array of accessories that can be utilized to optimize alignment even with children who have significant support and positioning needs. The Rifton Activity Chair can be used for various tasks, from meals to therapy sessions, and is designed to grow with the child. They also have an optional high low system so that they can be positioned at the family table or a child's play table. There are many types of adaptive chairs such as the Lecky Chair, Special Tomato, TherAdapt amongst others. Talk to your team to determine which best suits your child's needs. Trialing the one you think you like before purchasing is always a good idea if one is available.

Corner Chairs: This type of chair places the child on or close to the floor and has sides that mimic a corner, providing support for the child. It often promotes long sitting (sitting with legs straight in front), which is the first form of independent sitting that children achieve.

Bolster chairs: This type of chair consists of a seat back and a firm cylindrical cushion that the child sits on with one leg on either side. Straddling the seat in this manner maintains a wide base of support and puts the hips and pelvis in a stable position, providing more control.

Portable Seats: These chairs are portable seating systems that can be placed on regular chairs that one may find at a neighbor's house, restaurant or even a shopping cart or park bench. They provide additional support for a child that does not have independent sitting balance to allow them to sit in an otherwise unadapted seat. They are typically light weight and often foldable. Depending on the particular system, they can provide enough support to promote sitting for those with minimal to significant postural support needs. Some examples of these are:

HEAD SUPPORT

CP often affects muscle tone, coordination, and control, including those muscles responsible for holding the head upright. This leads to fatigue or inability to maintain proper posture without assistance. Furthermore, head control can be hard to develop as a baby's head makes up a large portion of their body weight. If a child has difficulty maintaining or controlling their head in an upright position, it is crucial that proper head support is provided for safety, comfort, and functional engagement in daily activities. Proper head and neck alignment is essential for safe eating and drinking. Staying in a forward flexed or extended posture for prolonged amounts of time, causes lengthening and further weakening of the muscles that are responsible to hold the head and neck upright. There are many different types of head supports. We will be covering a few of the most common ones here. Not all head supports are considered to be safe for use during transport. Any head support used in a car or bus MUST be graded for transport.

Head Pod: This device is unique in that it provides support from above, lifting and taking up part of the weight of the head. This allows the user to participate in holding up his/her head and develop control. It is also unique in that it does not provide support from under the chin. It therefore does not block the jaw from opening and chewing or prevent head rotation. It additionally allows a child to perform a chin tuck and engage in downward gaze, which is necessary when looking and engaging in any toys/items placed on a table or surface in front of them. The down side to the Head Pod is that it needs to be attached to a surface, such as a chair back or stander and cannot be used when sitting on the floor or other surface.

Hensinger Collar: This is a soft foam collar that wraps around the back of the neck and clips together in the front on the chest. It provides support under the head and jaw. It is soft and comfortable, but maintaining the correct alignment over extended periods of time can be difficult. This collar comes with an optional accessory to be mounted to a chair.

Danmar Side Opening Collar: this head support opens on the side with a quick-release buckle closure for easy on/off. It provides firm but gentle lifting of the chin, and lateral and occipital support of the head. This collar comes with an optional accessory to be mounted to a chair.

Headmaster Collar: This is a cervical collar that is light and airy. It consists of a small shelf for the chin to sit on and a round chest support and strap. It is open and allows access for children who may have a tracheostomy or may be on a ventilator.

LOOKING AHEAD: THE IMPORTANCE OF CUSTOMIZATION

It's essential to understand that adaptive equipment is not a one-size-fits-all solution. Every child with cerebral palsy is unique, and the equipment that works best for your child will depend on their individual needs and abilities. This is where the expertise of your team of physical, occupational and speech therapists becomes so helpful. Working with a therapist, you can determine which adaptive equipment will best suit your child's current abilities while allowing for future growth. Most importantly, focus on your needs and goals as well as the comfort of your child. Additionally, there are equipment clinics that specialize in assessment, fitting and choosing the appropriate choice for your child. Many of them have several options on hand to trial before you order. Another point to consider is that the clinic you choose for seating may not be the same clinic you choose for communication devices.

In future articles, we will dive deeper into specific categories of adaptive equipment, such as mobility aids, walkers and crutches, positioning devices, and so much more.

Introducing adaptive equipment into your child's life is an essential step toward improving their functional independence, comfort, and overall well-being. In this first article of our series, we have covered a more general overview of standers and adaptive seating systems. Each piece of equipment serves a unique purpose and can significantly benefit your child in different areas of life.

> Introducing adaptive equipment into your child's life is an essential step toward improving their functional independence, comfort, and overall well-being.

As you continue your journey with your child, remember that it's essential to explore different options and consult with medical professionals to find the right equipment for their specific needs. We hope this introduction helps you feel more informed and confident in making decisions or even just opening the lines of communication to start the conversation about your child's adaptive equipment.

Stay tuned for the next article in our series, where we will continue to explore additional adaptive tools and provide you with more helpful insights for supporting your child's development. ●

Q & A With Dr. Berkowitz

Dr. Dovid Berkowitz, Psy. D

Question 1: When I watch my daughter struggle and express her frustration, what are points that I can communicate to my child to calm her down?

Validate her feelings and help her come up with her own solutions. Use phrases such as "How can you solve this problem?", "What would make you feel better in this situation?", "What are some next steps you can take that will make this problem better?"

Question 2: Sometimes after a few failed attempts siblings jump in to help out. What do I tell them regarding helping their struggling sibling versus letting them figure it out, or helping in a way that's respectful and empowering?

The best way you can help somebody is by letting them help themselves. Obviously, you don't want them to fall, so you want to be there for them to support them. If you find yourself in a situation where you see that the sibling really cannot do it on their own, we need to help them in a way that shows them how to do it. So essentially you are modeling to them how to do it. If you could assist them, it's better than doing it for them. Modeling to your children how to support the sibling is the best way to teach the siblings.

Question 3: How do I teach my daughter the bounds of when to try again and again and when to push herself to ask for assistance when needed?

Like I mentioned before, I think we need to model this kind of behavior for them. Sometimes we run into issues that we have trouble dealing with. We need to show our children when we are working towards doing something that's difficult for us, as well as show them that it's okay to ask for help. It's ok to struggle; you can say, "This is really hard but I'm going to figure out how to do this", or, "I'm not sure how to do this but if I get a little bit of help then I'm sure I can do it".

Question 4: As I watch my child struggle physically, what thought can I think so I don't feel broken and pulled down while the behavior is happening?

We need to think to ourselves: My child is doing everything they can to be independent now and I'm going to support that. I'm going to encourage that and I'm going to be proud of them for doing everything that they try to do. I will be there to help them for anything that they need my assistance for but anything that they can do themselves, even if it takes a little bit longer, I'm not going to be frustrated. I'm going to have the patience for it because I know at the end of the day that if they can do it themselves, they're better off doing it on their own rather than me doing it for them.

> **The best way you can help somebody is by letting them help themselves.**

Question 5: What can I incorporate in my daily life, not during the struggle, so I don't get pulled down throughout the day or week when I watch my child struggle in their way?

Everybody needs self-care. I'll give the classic example: If someone is on the airplane and there's an emergency, first they put on their mask and then they put on the mask of the person sitting next to them. The reason for that is if you're not taking care of yourself, you're not going to be any good for anybody else. Everybody needs to find time for self-care for themselves. For some people that's taking a walk, for some people that's reading a book, for others that's getting a manicure. For some, it's being able to go to the *Rav's shiur*. Everybody needs to figure out what their self-care is. You need to know yourself and know what kind of self-care you need. This is going to help you be a better support for the people you are caring for. When you take care of yourself you have a better mindset and you'll be able to cope better with the adversity that's around you. You will ultimately be able to support the people around you much better.

Question 6: Is it worth it for me to put my child through all the painful therapies, exercises, stretching, braces and orthotics etc.? Maybe I should just let my kid be happy.

While "happiness" is important and we want our kids to be comfortable, at the same time we have to realize that there are certain things they need to do that will make a big difference for them in the future. For example, if a child isn't wearing their braces and not wearing their orthotics, they're not going to be able to bear weight properly. You can talk to your physical therapist about the other implications of this as well. As your child gets older it will make it much harder when you're trying to lift your child without the weight bearing skill.

So we will work with our children and we will support them. We will acknowledge when something is difficult and we will do the very best we can to make it as painless, stress-free and anxiety free as possible. We will motivate them, we will reward them and we will encourage them. Hopefully, they themselves will be able to recognize the progress that they're making by going through some of these things. At the same time, we must also be thoughtful about the interventions that we put your child through. Make sure that these are interventions that are scientifically proven, supported by your doctors and knowledgeable therapists, and that we're not just taking them for every weird intervention/unscientifically proven method that might be out there.

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

SCOLIOSIS SURGERY IN CEREBRAL PALSY

Noelle SB Whyte, MD

The incidence of scoliosis in children with cerebral palsy overall is twenty to twenty five percent. This incidence increases in children who have more severe involvement (e.g. patients who are wheelchair users for all mobility). Once scoliosis is diagnosed, your child may be referred to an orthopedic surgeon for management. Management may initially consist of observation, with serial radiographs performed 1 to 2 times per year. Sometimes bracing can be helpful to assist children in maintaining an upright posture during their daily activities. This can be helpful in allowing them to participate in more activities for socialization purposes and assist them in being able to better participate in their therapies. If the scoliosis appears to be progressive, surgery may be recommended.

Severe scoliosis can affect a child's lung function, their ability to tolerate being upright (especially if they rely on the use of a wheelchair for mobility), hygiene, and the caregivers' ability to transfer children easily. Should surgery be recommended, your orthopedic surgeon will want to ensure your child is healthy enough to undergo the procedure. The surgeon may talk with your child's other specialists to ensure they have appropriate nutrition, their heart and lungs are strong and healthy, and their other medical diagnoses are under control. Once your child is healthy enough to undergo the procedure, the surgery will take place. At C.S. Mott Children's Hospital in Ann Arbor, Michigan, some children with cerebral palsy may be candidates for spinal anesthesia to assist with postoperative pain control. This involves placing pain medicine into the spinal canal (similar to an epidural for pregnant women giving birth) and is performed by an anesthesiologist in the operating room when your child is asleep. This allows children to be transitioned to oral pain medications faster than if they had not received a spinal anesthetic. It is beneficial, as it can decrease the length of time children are in the hospital and provides a steadier state of pain control than pain medicine through an IV. The surgery is performed under general anesthesia. The surgeon will expose the area of the spine to be fused and will place strong, anchoring screws called pedicle screws into the vertebral bodies on each side of the spine. The pedicle screws are then connected with a rod on either side of the spine and the spine is straightened. Some surgeons will use intraoperative navigation systems to assist with placing the screws into the correct location in the pedicle of the vertebral bodies.

Children are then admitted to the hospital after surgery to monitor them for any potential complications in the immediate postoperative period. These could include infections in the lungs or in the urine. In addition, children with cerebral palsy who undergo spinal fusion are at increased risk of developing a postoperative ileus, a condition in which the gut shuts down and is unable to absorb nutrients. This can result in postoperative nausea and vomiting and predispose patients to developing lung infections. It is therefore important to monitor for signs of return of gut function before patients are restarted on their usual home diet. Patients are ready to be discharged home when their pain is under control, they can tolerate a normal diet, and they have been evaluated by a physical or occupational therapist and have had new medical equipment (e.g. shower chair, bedside commode, etc.) ordered, or old equipment updated (e.g. wheelchair, walker). Some surgeons will have families leave the surgical dressing in place until their follow-up appointment. Some surgeons may change the dressing before patients leave the hospital. Either way, families should monitor the dressing for any signs of new or worsening drainage, foul odor, or redness around the incision. In addition, children should be monitored for any signs of fever or worsening pain after discharge. If these are noted, the surgeon's office should be contacted to alert them, as this could be a sign of an early postoperative infection. Oftentimes, physical activity will need to be modified for a period of a few weeks after surgery. This may include limitations on involvement in sports, limitations on the patient's ability to bend or twist, and limitations in how much weight patients can pick up on their own. In addition, children who normally walk or use self-propelled mobility devices may need assistance to be mobile. During this time, caregivers will need to be available to help with activities of daily living (e.g. using the bathroom, walking/using wheelchairs, brushing teeth, combing hair, etc.).

Patients will often return to the clinic two to three weeks after surgery to assess the healing of the surgical incision. When given the go ahead, patients and caregivers can resume their normal hygiene protocol, including bathing or showering. If patients are involved in physical therapy at baseline, this can often be reinstated as soon as the surgical incision has been checked and noted to be healed. After three to six months, most surgeons will allow patients to return to their normal physical activities. Some families choose to do some additional physical therapy for strengthening purposes, but this is not always necessary. After the procedure, the surgeon will continue to monitor the patient anywhere from two to three times per year to ensure the fusion has healed and recovery is proceeding as expected. ●

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Scoliosis in Cerebral Palsy: What Families Need to Know

Marissa Muccio, PT

Brought to you by Marissa Muccio PT President
Scoliosis Specialty Center, NDT
trained, Schroth certified, member of SRS,
SOSORT, in conjunction with: Scoliosis Therapy
Centers 3D Bracing Specialist and advertisement

When people hear the word "scoliosis," they often think of teenagers wearing braces. This type of scoliosis, called Adolescent Idiopathic Scoliosis, is common, but many parents of children with cerebral palsy are surprised to learn that scoliosis can also affect their children. In CP, this is known as Neuromuscular Scoliosis.

What Is Scoliosis?

Scoliosis refers to an abnormal curvature of the spine. Historically, it has been described as a side-to-side shift, but we now understand that scoliosis can affect the spine in three dimensions, including front-to-back movements and rotation. An official diagnosis of scoliosis is made using an X-ray to measure the curve of the spine. If the curvature is 10 degrees or more, it is diagnosed as scoliosis.

For children with cerebral palsy, scoliosis often develops because of uneven neuromuscular control. CP affects how the brain sends signals to muscles, which can lead to imbalances in muscle strength and control on one side of the body as compared to the other. These imbalances can cause the spine to curve, especially as the child grows. In CP, scoliosis may worsen even after growth is complete due to the ongoing muscle imbalance. This is unlike other forms of scoliosis. Large curvatures can affect movement, comfort, and overall quality of life.

Many parents may think of scoliosis simply as a left-or-right curve or a bending of the spine, but it's actually a 3-dimensional change in the shape of the spine. Scoliosis affects the vertebrae, joints, and discs, causing them to rotate, not just misalign. This rotation changes how the spine supports the body, both in posture and movement. Traditional spine exercises may not be as effective because they're designed for a typical spine, not one that's affected by scoliosis. In fact, some exercises may worsen the curve's rotation due to the way the vertebrae wedge together. Scoliosis-specific physical therapy, such as the Schroth Method, focuses on assessing the spine's 3-dimensional shape change on x-ray and biomechanical movement patterns. Children with neuromuscular conditions may have very different types of scoliosis curves, affecting their head, neck, shoulders, trunk, pelvis, or legs. Understanding how scoliosis impacts your child's body, along with their specific condition, is key to choosing the right exercises and creating the best plan for their care.

Scoliosis-specific therapy can complement neuromuscular physical therapy for children with cerebral palsy by focusing on the curve-specific 3-dimensional aspects of postural alignment and spinal motor control. Following analysis of curve-specific measures from x-ray, we emphasize individualized exercises that promote the activation of the curve- specific deep stabilizing muscles to improve posture and decrease the asymmetrical loading of the scoliosis curvature. Neuromuscular physical therapy can incorporate these Schroth-based techniques to enhance motor control, balance, and functional movement, addressing skeletal alignment and neuromuscular deficits. This integrated approach may help improve overall posture, movement patterns, and quality of life for children with cerebral palsy, particularly those with scoliosis.

Managing Scoliosis in Children with Cerebral Palsy

For children with idiopathic scoliosis (the more common form), treatment options like bracing, physical therapy, and monitoring are well-established. However, children with neuromuscular scoliosis may need different approaches.

1. Bracing:

A brace is a custom-made plastic device that surrounds the spine and hips to control the curvature, particularly during growth. A Certified Prosthetist-Orthotist (CPO) will design the brace based on a scan or cast of the child's body. After fitting, the child will wear the brace, and an "In-Brace" X-ray will be taken to check the effect on the spine. Regular follow-up is essential to monitor for skin issues and assess the fit. While bracing cannot fully stop scoliosis from progressing in children with CP, it can help improve comfort and functional alignment. Studies suggest that bracing may slow the progression of the curvature, but its effectiveness varies depending on the child's abilities and curvature size.

2. Physical Therapy (PT):

Physical therapy is an important part of managing CP at every age. For scoliosis, specialized physical therapy is available to address the three-dimensional changes in the spine. This advanced therapy focuses on specific exercises and techniques to address the unique 3-dimensional spinal alignment, reduce progression, and improve motor function. Although research on scoliosis-specific therapy for CP is still limited, trained PTs can apply these techniques to help manage the condition, either through direct treatment or in collaboration with general physical therapists. Regular PT can also help maintain mobility and function throughout the child's life.

> **In CP, scoliosis may worsen even after growth is complete due to the ongoing muscle imbalance.**

A Team Approach to Care

Managing scoliosis in children with cerebral palsy requires a comprehensive, team-based approach. A knowledgeable team led by patients/family, including orthopedic specialists, physical therapists, and orthotists, can provide the best care plan for each child's unique needs. With regular monitoring and tailored treatments, families can work together with healthcare providers to help minimize the impact of scoliosis on their child's life.

By understanding the potential for scoliosis and seeking appropriate care, families can help children with cerebral palsy lead a more comfortable, active life. ●

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Smiles Ahead

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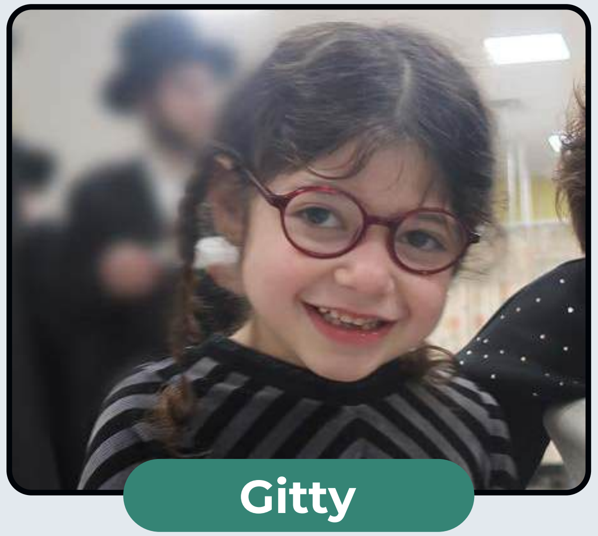

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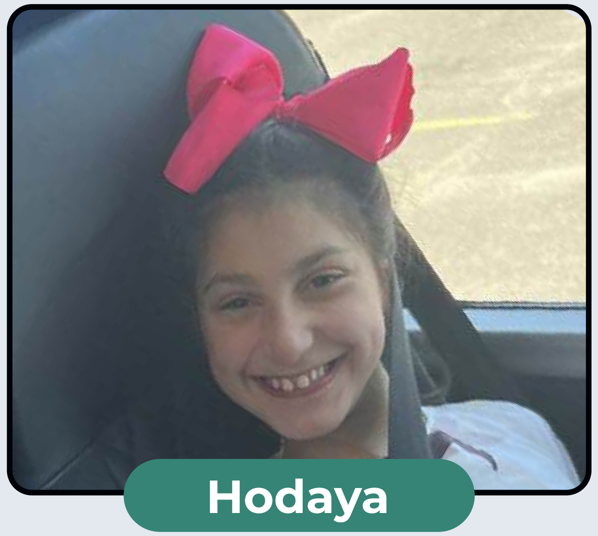

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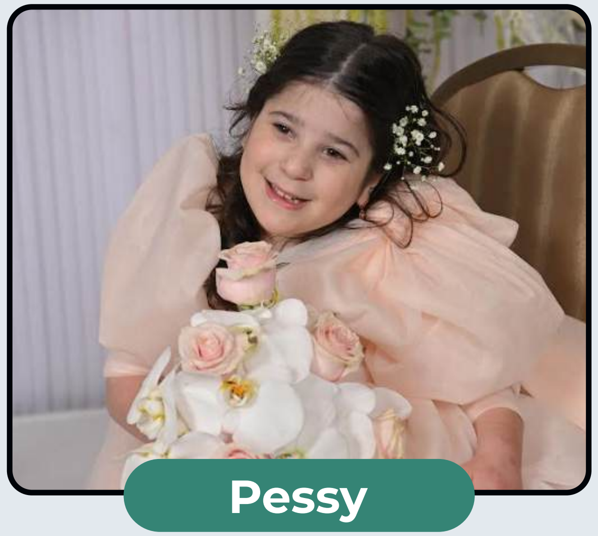

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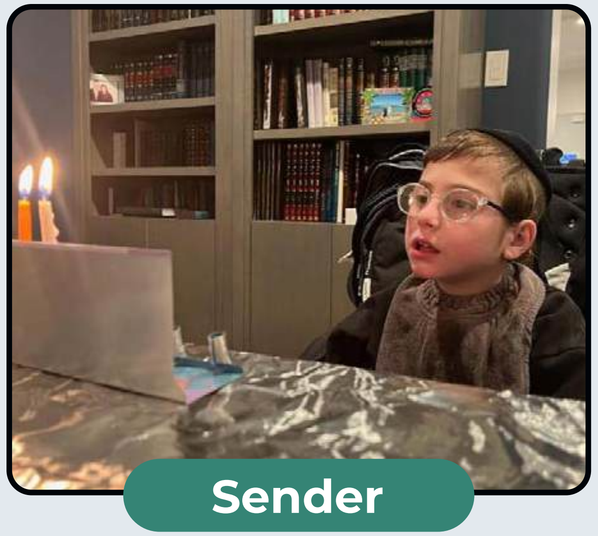


Sender

Shaya

Tova

Yisroel

Yitzchok

Yossi

CHIZUK BOOST

Rabbi Shia Hershkowitz

The late Mirrer Rosh Yeshiva, Reb Nosson Tzvi Finkel zt'l, suffered from Parkinson's disease for the last twenty-eight years of his life. Despite his pain and physical limitations, he pushed himself to maintain his regular schedule of learning and teaching *Torah*. On one tough day, he struggled to walk into the *Bais Midrash*, supported by two *talmidim* on either side. The spasms were so intense, he could not control them. Reb Nosson Tzvi zt'l took a deep breath, started the *shiur*, and had to stop. He tried again and again. Finally, he asked for a pen and paper and laboriously wrote two words, נסתי, סליחה; 'I tried, I'm sorry.' He then struggled out of the *Bais Midrash* without giving the *shiur*.

The *Rosh Yeshiva* may not have given a *shiur* that day, but he taught an important lesson. *Hashem* expects us to make an effort and rely on Him; He will determine the result.

Megillas Esther, part of *Torah Sh'bichsav*, does not openly record *Hashem's* name. A close study reveals *Hashem's* name in the first or last letters of words in *pesukim* describing the climactic events in the *megillah*. When *Haman* persuades Achashverosh to kill Vashti, he says, לא על המלך לבדו עוותה ושתי המלכה, 'Not only against your Majesty has Vashti committed an offense.' The *sofei teivos* of the last four words of the phrase reveal the name of *Hashem*. There are twelve such clues scattered throughout the *megillah*, and at every critical part of the story, *Hashem* covertly orchestrates events to guarantee the survival of the Jewish nation.

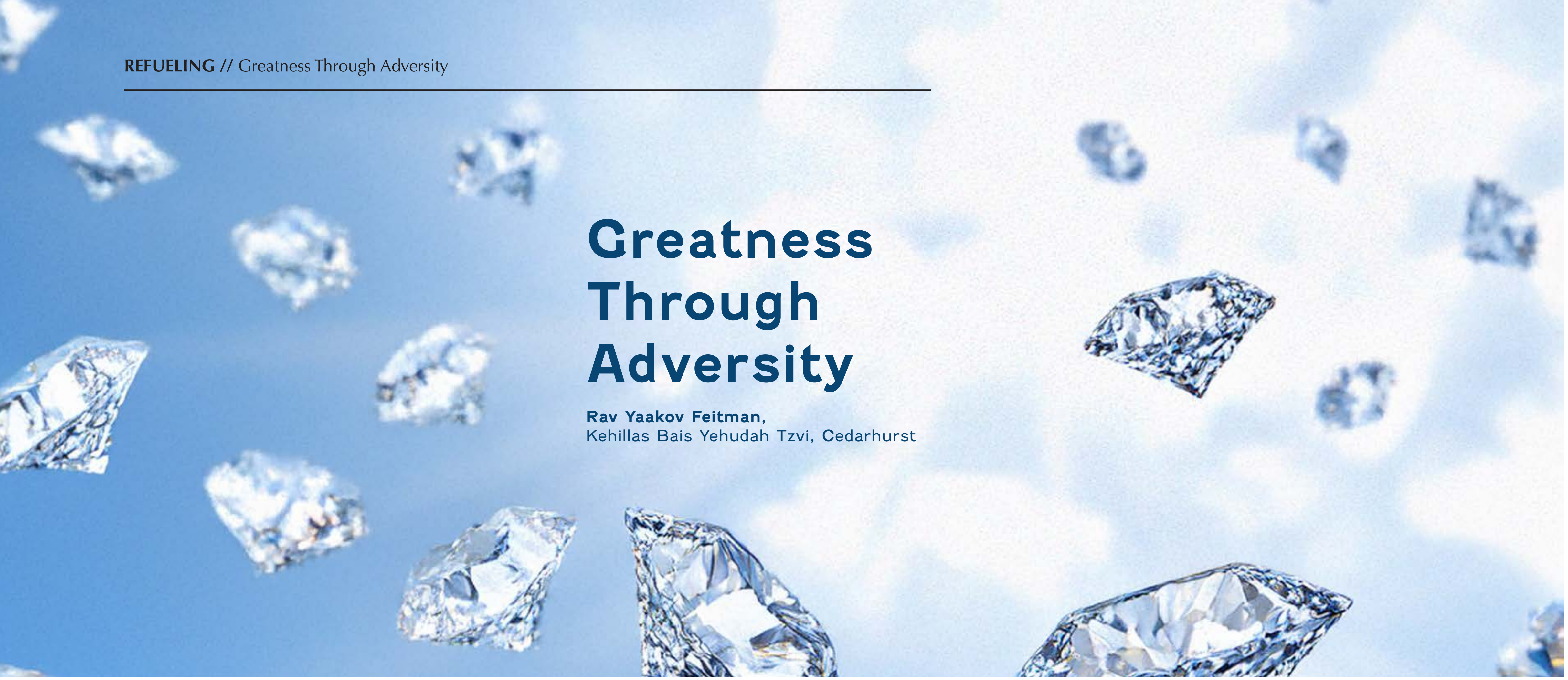
> Hashem wants us to understand that our struggles in life are dearer to Him than our triumphs. Our challenges are the means to spiritual growth and character development.

After Yakov Avinu fought and overcame the *Malach* of Eisav, the *Malach* gave Yakov the following beracha. ויאמר לא יעקב יאמר עוד שמך כי אם ישראל כי שרית עם אלוקים ועם אנשים ותוכל. 'Your name shall no longer be called Yakov, but Yisrael, because you battled with (an angel of) *Hashem* and with men, and you prevailed.' Why does the *Torah* emphasize the battle, כי שרית, rather than Yakov's victory, ותוכל? The reason, tell us *Chazal*, is because *Hashem* wants us to understand that our struggles in life are dearer to Him than our triumphs. Our challenges are the means to spiritual growth and character development.

We see this concept once again in this story through the *mitzvah* of not eating the גיד הנשה (sciatic nerve). על כן לא יאכלו בני ישראל את גיד הנשה...עד היום הזה כי נגע בכף ירך יעקב בגיד הנשה. 'Therefore, *Bnei Yisrael* did not eat the גיד הנשה until this day because the *malach* struck Yakov at his גיד הנשה.' *Hashem* gave us this *mitzvah* so that we remember that the *malach* of Eisav attacked Yakov and wounded him. This point highlights that how we attack our challenges is more meaningful than the satisfaction of victory. Our determination is so very precious to *Hashem*.

Hashem cherishes the struggles of parents raising their very often extremely challenging special children. There is a very powerful story that brings out this concept. Reb Boruch approached Reb Yaakov Meir Schechter shlit"a, with feelings of despair. Reb Boruch is the father of many children. Some of his children suffer from disabilities. "I am ready to give up!" Reb Boruch said in agony. "My disabled children take away all my energy! I want to give up on them. What do I need them for? *Baruch Hashem* I have some children who are succeeding, and easy to raise. Why do I need to raise disabled children too, where every struggle seems to end in failure?" Reb Yaakov Meir Schechter looked at Reb Boruch and answered, "After one hundred and twenty, you will come up to *shamayim*. Which of the children are you going to show that you raised? The ones you struggled with to no end and didn't succeed or the children you *Baruch Hashem* raised without much effort?"

Adopting this outlook will certainly change our lives. We try, since that is what *Hashem* wants. Ultimately, our reward will be that much more significant, לפום צערא אגרא. The harder the struggle, the more abundant the reward. ●



Greatness Through Adversity

Rav Yaakov Feitman,
Kehillas Bais Yehudah Tzvi, Cedarhurst

I was reading the CPUU Magazine and was struck by the beautiful pictures of beautiful children. Their smiles light up the page, but most importantly, they touch my soul and my heart. The following words are my only way to pay back a tiny part of the joy they brought me and, I am sure, they bring to *Hashem* every day.

Sefer Bereishis is full of enormous lessons for all of us about life. But one of the most profound is a lesson from what is not there. For instance, Yaakov *Avinu* learned for fourteen years in the *Yeshiva* of Shem and Aiver. *Chazal* tell us that he didn't waste a moment, even on sleep, in that unique environment and time in his life. But the *Torah* itself never mentions those crucial years. Yitzchok also learned there for three years, but we only know that from the *Medrash* (*Bereishis Rabbah 56:11*). During the last seventeen years of Yaakov's life, he lived in Mitzrayim, in the land of Goshen. He was surrounded by his children and grandchildren, *shepped* much *nachas* and learned and taught much *Torah*. But the closest we come to hearing about it in the *Torah* is the first *posuk* in *Parshas Vayechi* which merely states that Yaakov lived in *Mitzrayim*. Why didn't the *Torah* reveal these times of greatness in the lives of our *Avos*?

To deepen the question, the *Torah* does elaborate upon Yaakov's battles with Esav himself; with his heavenly representative; with Lavan; and the massive difficulties with Dinah and with Yosef. Why do we seem to hear only about the troubles, tests and distress they experienced in life? Rav Chizkiyahu Yosef Karelenstein answers with a simple but profound concept. People don't grow as much from their times of tranquility and serenity as from their troubles and suffering. Yaakov Avinu's son Dan had only one child whose name was Chushim. He was deaf, which undoubtedly carried all of the *nisyonos* of raising such a child. Yet, as Rav Chaim Shmuelevich zt"l, Rosh Yeshivas Mir points out, he was the one who triumphed over Esav at a precarious moment in *Klal Yisrael's* history. Why him? The answer is that because his parents had to invest so much time into his growth, development, *chinuch* and personality, he became somebody truly special.

Those who deal constantly with dystonia and hypertonia, spasticity and seizures do indeed need and deserve *chizuk*. But, as the *Ramchal* often writes in *Derech Hashem*, it is the tests of life which elevate us to heights we could not achieve without triumphing over struggles. The hospitalizations, emergencies and moments of anxiety and depression are one of *Hashem's* ways of propelling us to *gadlus*. Rav Karelenstein offers an amazing mashal for this aspect of our lives:

A man is walking near a skyscraper in Manhattan and suddenly feels a rock hit his head. He looks up to discover the source of his pain and gets hit again. Now he is really angry and seeks to avoid this strange onslaught. However, looking down at the stones, he realizes that they are all actually diamonds. Someone exiting the building reveals that an elderly jeweler got angry about something in his craft and decided to throw the offending objects out the window. He announced that he no longer wants them and is throwing them away. Now, the passerby changes his mind and begins to pray. "Please *Hashem*, send me more of these jewels. If the owner doesn't want them, I will be happy to have them hit me on the head again."

At *Matan Torah*, the *Torah* records that the elders "saw *Hashem* and under His feet was the likeness of sapphire brickwork" (Shemos 24:10). Rashi tells us that this brickwork was in front of *Hashem* during the bondage in Mitzrayim to remind Him of the pain of His people. The medrash teaches us that although the bricks we had to produce were extremely painful to come by and caused us great anguish, they were in reality the precious stones which prepared us to be able to receive the *Torah*. With *Torah Shebaal Peh* we find the same process as with *Torah Shebichsav*. Rebbe Akiva is the major *Tanna* of the *Oral Torah*. Until he was forty years old, he hadn't learned anything at all. Then, as an adult, he sat in the kindergarten class until he could learn *Torah* for real. Later, he grew to the point that when Moshe Rabbeinu viewed all the future generations and saw Rebbe Akiva, he asked *Hashem*, "You have such a person, yet You wish to give the *Torah* though me?" In other words, it is adversity and *nisyonos* which make a person ready for greatness.

No one wants tests and we even say in many prayers, "Please Hashem, not through arduous tests." But once the stones hit us in the head, we must try to appreciate that they are diamonds in disguise. They are what make us grow spiritually and elevate us to heights we would never achieve without them. Yaakov Avinu did indeed originally wish to live in tranquility (*Rashi*, beginning of *Vayechi*), but Hashem sent him tests instead. Of course, Yaakov didn't want an untroubled retirement to play golf. He thought that he had experienced enough tests in his life that he could now concentrate on *Torah* in an undisturbed way. But *Hashem* decided that Yaakov still had growth which required more *nisyonos*. It would seem that Avrohom Avinu was the original *maaseh avos* for this *siman labonim*. He passed nine tests with flying colors and may have thought that he had graduated from *nisayon* school. But it was the *akeidah* which ended up being our greatest *zechus* as a nation and which enabled all future generations to survive the rigors and challenges of all the exiles. What I often hear from people who have gone through difficult times is the question, "When will all this be over?" I surely don't know the answer but if we can try to remember that diamonds are falling from the sky, it may be just a tiny bit easier to be willing to accept a few more.

Finally, a word from my *rebbe*, Rav Yitzchok Hutner zt"l. The *posuk* (*Mishlei 24*:16) tells us that a *tzaddik* falls seven times and gets up. He explains that this doesn't mean that despite falling, the *tzadik* is able to arise. It means that because he has fallen and been hurt, he gets up and is better than before. Clearly, those who live with the tests of CP in their family may feel that they have been hit many more than seven times. They are down and then get up again, over and over. But they are building and laying the bricks of the future *Bais Hamikdash*. The *Bais Hamikdash* was not permitted to be built by cutting precious stones. It had to be done with the *Shamir*, which cut gently and later, when that worm was no longer available, outside the *Bais Hamikdash* itself. The diamonds depicted on the pages of this magazine will shine more brightly than anyone when *Moshiach* comes to inspect us. He will surely be grateful to everyone who embraced, loved and cherished them, so their holy *neshamos* made us all worthy enough to merit his coming *bimeheirah b'yameinu amein.* ●

The Master Plan

Mrs. Dina Smith

We may wonder when we see some people suffer; especially young children. "Why do simple tasks like tying shoes or walking up steps have to be such a struggle for them? Why can't they live a carefree life without constantly needing therapy and doctor appointments?"

Instead of answers, we rely on *Emunah*. Instead of frustration, we learn acceptance. Here are some points to keep in mind:

***Hashem* made a perfect world and keeps it running in perfect order!**

At the end of the six days of creation *Hashem* looked at the newly created world to evaluate it and to see if it needed any correction. והנה טוב מאד (בראשית א' לא)

And behold it was very good; everything was perfect! These words continue to resonate throughout history. Just like *Hashem* made a flawless world, He continues to run it in a beautiful way. Everything runs in sync and every person and creation is here for a purpose. Furthermore, every challenge and encounter that a person and his family have is tailor made for them.

A case in point from the *Chumash* is when Yosef was sold by his brothers to passing merchants. It was a very dark time for him.

At age seventeen, he was wrenched from his loving father and reduced to a lowly slave. *Rashi* in *Parshas Vayeshev* states a remarkable thing. Arab merchants like the ones who bought Yosef usually carried kerosene and other foul-smelling items. *Hashem* made sure for the sake of Yosef that this particular time they were carrying with them various sweet-smelling spices. Why? So that the *tzadik* Yosef should only have pleasant smells accompanying him on his journey. The question is obvious. What difference would the sweet-smelling spices make to Yosef in his terrible ordeal? Several answers are given to this perplexing question:

Here are two answers that are relevant to any challenge a person may face. The first is that we can understand from this incident that even in the darkest times, *Hashem* is always with us. *Hashem* in His wisdom had a plan for Yosef but made a gesture to show him that He is still looking out for him with love. Have you ever encountered a special "hug" from *Hashem* which gave you encouragement?

The *Bais HaLevi* gives a second insight on this topic. He explains that every bit of a person's life challenges is measured out in precise detail. No one will get a drop more or less than what is destined for him. He won't even experience a bad odor that was not meant for him to endure. Have you ever experienced a time where certain difficulties were made so much easier and things that were usually complicated went smoothly?

We only see a small glimpse of the whole picture.

Picture witnessing this: A. A man wielding a knife pierces it into a person's stomach! B. A child is crying bitterly as his mother gives him several hard smacks. C. In shul, the gabbai gives the simpletons most of the *aliyos* leaving out more respected *Rabbis* in who are attendance.

Is there any rhyme and reason in the above scenarios? Absolutely! In fact, in each scenario there was careful contemplation by those involved. Can you figure out what really happened? Read on….

A. The man with the knife was a kind surgeon and was slicing open the stomach of his patient in order to remove a dangerous tumor.

B. The parent just grabbed the child off the street saving him from an oncoming, racing car. To make an impact on the child never to run into the street again, he was given a smack.

> *Instead of answers, we rely on Emunah.*
>
> *Instead of frustration, we learn acceptance.*

C. Being a visitor in town, one can never know that the *gabbai* picked one Shabbos a year to acknowledge the simple folks with *aliyos*. That was this particular Shabbos.

As is evident from these scenarios, if one does not see the whole picture, he cannot possibly comprehend the happenings clearly. We, too, only see part of the whole picture and may wonder about the circumstances one is placed in. Our view can be compared to one seeing the other side of a needlepoint or the back side of the stage.

In *Hashem's* eyes, the whole history of the world is like an open book with a perfect view of the past present and future. We are just visitors on this world and do not see how *Hashem* orchestrates everything based on many factors until every piece fits together to create an exquisite puzzle.

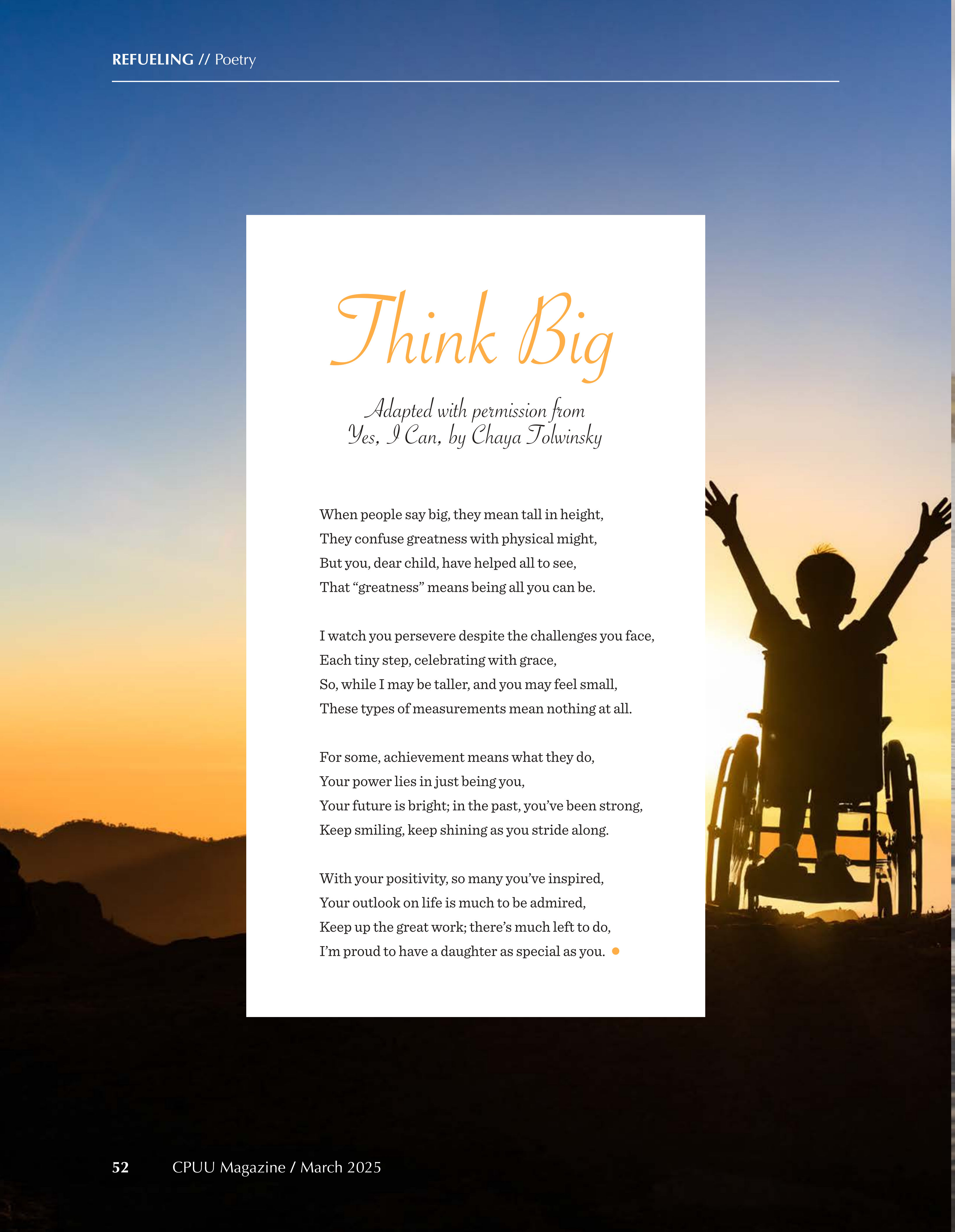
***Hashem* loves us, his dear children, and therefore wants only the best for us.**

Although *David Hamelech* was beset by many hardships, he felt secure with the knowledge that *Hashem* is taking care of him through it all. In *Tehillim*, he describes his trust in *Hashem* as an infant in his mother's loving embrace who has total reliance on her. When, like *David Hamelech*, we realize that *Hashem* has mapped out our life with our best interest in mind, we can overcome any stumbling block and transform it to a stepping stone. With acceptance of our circumstances comes the ability to forge on in life with renewed energy!

There was a couple who had a baby after many years of waiting. Alas, the baby was born with severe complications and even as time passed, he lay in a crib barely able to function. A visitor to the house was astounded to hear the father of this child say the following: "After so many years of waiting, look what a precious gift Hashem has granted us!" Isn't every *yiddishe neshama* sent in a Jewish child a treasure?

We are all part of the master plan. At the end of his life, my father, Harav Chaim Baruch Wolpin זצ"ל, was experiencing many *yissurim*. One morning he woke up with renewed strength and emotionally shared a dream he had during the night. His rebbe muvhak, Reb Reuven Grodzovsky זצ"ל, came to him in a dream and shared with him the following thought: The *Gemara* mentions the fact that all of the things of creation were made with their consent. This means that every living thing was happy to be what it was chosen to be. Question: why would a mouse agree to be such a lowly, unpopular creature? His *rebbe* answered the question: because he was happy to complete the creation for he knew it was part of *Hashem's* plan. My father got the message. He acknowledged that whatever he was going through was part of the master plan and he was ready to accept it with love.

I am sure you are all enjoying your special needs children. These precious children are part of *Hashem's* master plan. They teach us to appreciate even seemingly small accomplishments in life and to focus on each gift from *Hashem*. May they continue enriching and elevating your lives! May we all greet *Mashiach* soon when sickness and disabilities things of the past! ●



Think Big

Adapted with permission from
Yes, I Can, by Chaya Tolwinsky

When people say big, they mean tall in height,
They confuse greatness with physical might,
But you, dear child, have helped all to see,
That "greatness" means being all you can be.

I watch you persevere despite the challenges you face,
Each tiny step, celebrating with grace,
So, while I may be taller, and you may feel small,
These types of measurements mean nothing at all.

For some, achievement means what they do,
Your power lies in just being you,
Your future is bright; in the past, you've been strong,
Keep smiling, keep shining as you stride along.

With your positivity, so many you've inspired,
Your outlook on life is much to be admired,
Keep up the great work; there's much left to do,
I'm proud to have a daughter as special as you.

Ripples of Illusion

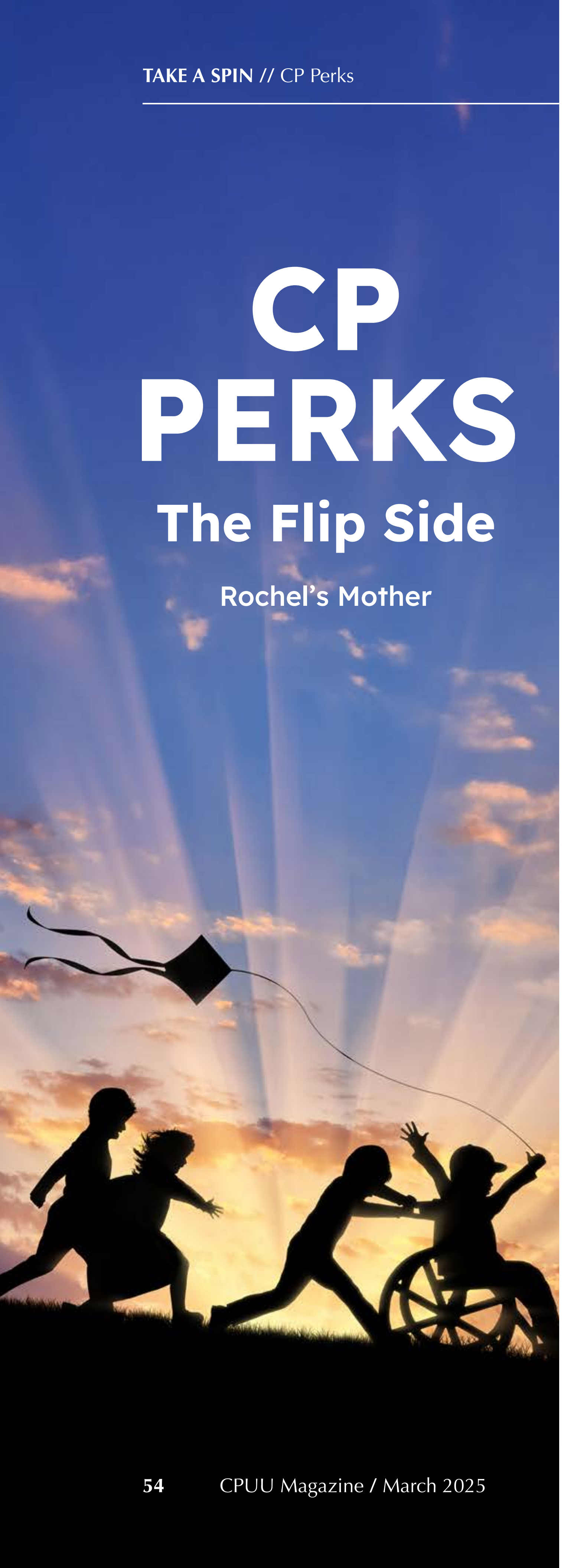
Nechumelle Jacobs

Looking at swans swimming in a lake
It seems picture perfect with nary a quake
We may feel jealous, their life seems so serene
But the ripples beneath the surface, are simply not seen

Likewise, people show the world an outward illusion
Don't become impressed, it's only a delusion
We all have inner struggles, in some strength or form
But only to the *rotzon Hashem* do I need to conform

We each have our own path, or water we must tread
Don't let externals put you off, but instead
As people cover up their difficulties or trial
Remember, there's often pain hidden behind the smile

Just swim along calmly, enjoy every minute
Cuz' we're all playing the same game, and are equally in it
Stride with the current, don't fight the seas
Feel the serenity as you swim through with a breeze.



CP PERKS

The Flip Side

Rochel's Mother

My son loves the card game Flip-It, which he learned from his Cheder friends, and he likes me to play it with him. Each player picks a card from the deck and flips it; whichever player's card lands face-up wins both cards. I love it, too, because it has taught me to Flip-It.

Comparatively, if having a child with CP would be a game of Flip-It, be an all-winners game. Every single flipped card is permanently fixed to face-up. Here are some cards that help me Flip-It and always land face-up.

- **Hashem:** First and foremost is a constant connection with the Aibershter. This card is not double sided - everything Hashem does is good. Really everyone has this winning card in their possession but those of us who are lucky to have a CP package have this card out and in front of us at all times.

- **Gratitude:** It's all about noticing the tiniest details and the blessings embedded within; the bus shows up on time, or when Rochel reaches out for something, or when she vocalizes simple sounds trying to communicate.

- **Self-Work:** This card sometimes lands face down, and I have to consciously Flip-It over myself. Consistency is not my strong point, yet being Rochel's primary caregiver forces me to be consistent. I acknowledge my efforts and congratulate myself when I place her immobilizers on her or administer the nightly g-tube feed for the umpteenth time.

- **Teachers, Therapists, and Paras:** I treasure the connections I built with Rochel's early intervention specialists and now with the excellent staff at her school. Their devotion and encouragement are key to Rochel's successful development.

- **Chessed Volunteers:** This card can be either face up or face down, depending on the family situation. My children are still young so having teenage girls to help in the house is a real plus. There are many delightful girls who give up their free time to interact with Rochel and entertain her. Rochel was incredibly proud to present my mother-in-law with a kugel she made with her 'Lev-with-Love' volunteer.

- **Appointments:** When this card lands face side up, we notice the pretty trees, lakes and rivers on our travels up and down the NJ Turnpike or the different towns at many of the exits off the Garden State Parkway. I am not familiar with the upsides of Manhattan travels but I am sure that there are others that are.

- **Vehicle:** The joys and benefits of having a highly recognizable mode of transportation is one of my favorites. First of all, I use the "handicap" oversized van as a license to have the right of way on the street. But I have to do this with caution because of the second benefit, and that is that I am easily identifiable. Anyone, at any given moment can know where I am. It's as clear as the bright sun.

I've got many more winning cards in my Flip-It deck. The game is not over yet, just keep on flipping! ●

Orthotics and Braces

Kevin Holl

SWASH BRACE

You might have heard his name before. Kevin Holl of Elite Orthotics and Prosthetics has built a reputation among the frum population as the go-to orthotist for individuals with CP and other disabilities. In this exclusive interview, Kevin discusses different kinds of orthotics, identifying the pros and cons of each, so you can ensure that your child gets the best braces for their needs.

Kevin shares that within the CP population, there's a wide variety of patients, some of whom have high-muscle tone and some of whom have low-muscle tone. For the high-tone population, he primarily creates custom articulated AFOs while for the low-tone population, he uses mostly SMOs. Depending on the patient's disability, the goal of the orthotics will vary, but the overall goal for every patient is to provide them with the support they need to maximize their capabilities.

Although Kevin is a specialist in the field of orthotics for individuals with special needs, he feels that it's always important for him to speak with the patient's family members, doctors, teachers, and therapists as they spend a lot more time with the patient. They know the patient much better than he does, and are therefore able to point out different things they notice.

Given that an orthotist's evaluations are short and not too frequent, it is vital for him to get feedback from the patient's family members and interventionists. As an orthotist, Kevin says he has the luxury of making his own braces. Over 75% of the braces that he fits his patients with are custom-made, which is why his patients have experienced such a high success rate.

While some people doubt the positive impact orthotics can have, Kevin believes that the only way braces can do more harm than good is if the orthotic or brace is not custom made or properly fitted. If they're fitted properly, and they do not result in positive change, the worst thing is that the patient is simply wearing them. In general, wearing braces is beneficial to the patient.

There usually isn't a situation where braces aren't good. However, not all patients can tolerate wearing them. In such cases, the correct solution might be to avoid braces, or just have the patient wear them at night. It's important for the orthotist to have a conversation with the parent to decide what the best plan of action would be.

Now let's discuss braces at length.

STANDARD ORTHOTICS

The Chipmunk

This is a low-profile, moderate-control shoe insert that can be easily purchased over the counter. It is usually worn to provide better foot and ankle positioning, such as arch support. Because it is a low-profile orthotic, Chipmunks can be worn in a standard shoe throughout the day, starting with a full-time wear schedule. They are usually worn by patients with low muscle tone and those with mild valgus pronation.

The Chipmunk shoe inserts are sometimes worn with other braces, such as a Toe-off, also known as a KiddieGAIT in the children's population. The advantage of this orthotics is that it's a very lightweight carbon fiber brace. The disadvantage is that as an off-the-shelf item, you're limited as far as the amount of control the orthotic can have because they aren't custom fit.

DEPENDING ON THE PATIENT'S DISABILITY, THE GOAL OF THE ORTHOTICS WILL VARY, BUT THE OVERALL GOAL FOR EVERY PATIENT IS TO PROVIDE THEM WITH THE SUPPORT THEY NEED TO MAXIMIZE THEIR CAPABILITIES.

UCBL Orthotic

This is a higher-profile version of The Chipmunk insert, however the UCBL orthotic is custom-made to fit the patient. It is constructed from hard plastic, and features a higher trim line than other arch supports. This provides a solid platform for the foot to rest on, which aids in controlling the alignment of the foot and ankle during walking and running.

UCBL orthotics are used for patients with excessive pronation or supination which causes the foot to roll inward or outward while walking. They help control the ankle joint, and aid in reducing pain and improving gait. UCBL orthotics are also a great option for preventing these issues from deteriorating when first detected.

AFO – ANKLE FOOT ORTHOSES

SMO - Supra-Malleolar Orthosis

SMO braces extend from the foot arch to just above the ankle, specifically providing control and support to the ankle joint. These orthotics are custom made to fit the patient so that they are comfortable and work effectively. They are often worn by individuals with neuromuscular deficits which affect their muscle control and stability. These braces provide external support, helping maintain better balance and prevent movements that can lead to other problems.

Denver T

A higher-profile SMO, the Denver T originated in Denver, CO hence its name. It has a different design which lends to it giving more control than the standard SMO brace. The Denver T helps with more than just joint alignment, so it's the preferred choice for patients who need to work on their dorsiflexion or plantarflexion, as it allows for more active movement than the standard SMO.

Turtle Brace

The Turtle brace is another kind of brace that works very well for specific disabilities. These braces have a fairly low-profile design with a tempered front so they can be easily folded. Turtle braces limit or decrease the amount of dorsiflexion and plantarflexion and work well for joint angles or any deformities of the valgus. Due to its free-fold design, multiple joints are able to receive a better fit.

Interesting Note: All custom orthotics are delineated AFOs (Ankle-Foot Orthoses) built to fit the patient's needs. Any orthotic suited for the areas below the knee joint, such as the SMO and Denver T orthotics, is an AFO. Anything above the ankle falls into the categories we will now elaborate on.

K-AFO – KNEE-ANKLE FOOT ORTHOSES

K-AFOs are orthotics that extend up to include the knee joint (that's the letter K before AFO), designed to control movement and support the lower limb joints. They come in various designs, depending on the individual's needs and the specific condition being treated. K-AFOs can be designed conventionally and made super durable to provide good support.

They can also be made using molded plastic, allowing for a lighter orthotic with a more customized fit. These are called Thermoplastic K-AFO.

Each K-AFO has a brace component for the foot and ankle, the knee, and the calf in between. With built-in brackets, these orthotics can be locked into place to prevent atypical joint motion while allowing for regular joint flexing.

HKAFO – HIP-KNEE-ANKLE FOOT ORTHOSES

HK-AFOs extend even higher, reaching the hip joint and allowing for comprehensive support from the hip down. These orthotics control hip motion, ensuring normal movement of the pelvic joints while stabilizing the knee and ankle joints. HK-AFOs are often used for patients lacking gluteal muscles who need joint stabilization, for example those with spina bifida, as they can be made with lockable slots based on the patient's needs.

HIP BRACE

The SWASH brace

Different from the multi-joint orthotics, the SWASH is a pelvic band without any locks. Interestingly, the SWASH brace was developed by an optometrist who had a daughter with cerebral palsy. She constantly crossed her legs when she walked. The optometrist developed the SWASH brace to be a free-motion joint that attaches the pelvic band to the thigh post. The joint can be adjusted to increase or decrease the angle of the hip joint.

The SWASH brace is primarily used for people with scissor gait or AD-ductor tone but is also sometimes used to keep hip dysplasia in proper alignment. It's a highly adjustable belt that can be a super effective option for the right patient.

TLSO – THORACO LUMBAR VENTRAL ORTHOSIS

Thoracolumbar ventral orthosis (TLSO) is a category of splints named for the body parts they brace. There are hundreds of variations, each serving a different purpose or a combination of purposes. Soft TLSOs are used for patients with scoliosis, osteoarthritis, and other disabilities caused by muscle imbalance. Standard/hard TLSOs are often used for posturing and ambulation, assisting individuals with muscular disabilities in walking and getting around.

Another kind of TLSO is called a TMO or a TRO which is like a custom, soft TLSO brace. These orthotics utilize compression as well as elasticity to create postural support. Some have plastic reinforcements while others have a frame system that may be more supportive. There are also braces with a soft foam on the inside and a plastic shell on the outside. These are often created or modified to treat scoliosis.

BENIK ELBOW AND HAND SPLINTS

The Benik company has a full line of various pediatric hand orthoses, some assisting with the full range of motion while others are lower-profile. It's important to get a recommendation from an orthotist for the kind of hand splints your child needs. Some individuals may need to limit their range of motion, while others may need to increase their range of motion.

A FEW IMPORTANT POINTS

When it comes to replacing braces, insurance companies allow you to do so once a year, which is generally an appropriate amount of time between replacements.

At Elite Orthotics and Prosthetics, the replacement frequency depends on the age and situation of the patient. Often, the patients come in for a 6-month follow-up to assess their progress and the effectiveness of the orthotics. If needed, their brace is adjusted or replaced.

When choosing an orthotist for your child, it's important to find someone open to hearing and accepting input from the child's caregivers. As mentioned, many people in the child's life spend more time with them than the orthotist does. An orthotist needs to be receptive to the comments, suggestions, and concerns of the family members and caretakers involved.

Kevin Holl sees clients at his practice, Elite Orthotics and Prosthetics, with offices in both Springfield and Eatontown, New Jersey. He works with the physically disabled population at large, and specifically with many cerebral palsy patients.

Kevin can be reached through his office via phone or email at 732-795-0603 oreopadmin@eliteop.net. You can also reach out through his website https://www.eliteop.com/ ●

Kevin Holl founded his practice Elite O&P in 2018, with the vision of providing the highest quality orthopedic bracing in the area. His experienced team of Orthotists, Prosthetists, and DME fitters are American board-certified and New Jersey-licensed practitioners. Elite O&P carries a full line of orthopedic bracing for spinal, lower, and upper extremities from all the major manufacturers and is the leader of custom fabricated bracing, servicing both the New Jersey and New York areas. Kevin's office has a friendly and relaxed atmosphere where every patient feels comfortable knowing that highly trained professionals are meeting their every need.

TURTLE BRACE

HAND SPLINT

Orthotist Providers

Boston Orthotics & Prosthetics
Bostonoandp.com
customerservice@bostonoandp.com
1-800-262-2235
NJ: 201-597-4300
964 Kinderkamack Rd, River Edge, NJ 07661
NY: 212-727-2011
30 East 40th Street Suite 905, New York, NY 10016
Maryland: 443-440-5550
49 Old Solomons Island Rd. Suite 205, Annapolis, MD 21401

HSS | Hospital for Special Surgery
hss.edu
irollac@hss.edu
212-606-1000
NY: 212-606-1906
431 East 73rd Street New York, NY 10021
NJ: 201-599-8000
140 East Ridgewood Avenue, Suite 175 S. Paramus, NJ 07652

Paley Orthopedic & Spine Institute
paleyinstitute.org
mdobbs@paleyinstitute.org
844-714-5293
Florida:
901 45th Street Kimmel Building, West Palm Beach, FL 33407

East Coast Orthotic & Prosthetic Corp
ec-op.com
info@eastcoastoandp.com
888- 400-8934
75 Burt Drive, Deer Park, NY 11729-5701
NY: 347-389-1755
norbert.marx@ec-op.com
Norbert Marx, CPO, Prosthetist/Orthotist
326 2nd Ave New York, NY 10003
NJ: 201-943-4448
39 Broad Avenue, Palisades Park, NJ 07650

Orthodesigns
Andrew Tse
Upper East Side: 212-396-3901
420 E 82nd St # 1e, New York, NY 10028

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eliteop.com
eopadmin@eliteop.net
732-795-0603
Kevin Holl
NJ: Springfield, NJ, Eatontown, NJ

Harry J. Lawall & Son inc. Prosthetics and Orthotics
Lawall.com
patient@lawall.com
1- 800-735-4627
Wayne Lawall: Regional Manager
215-620-2460
(As a side note: Wayne Lawall has been servicing the students at SCHI school for many years.)

Your Take

Would you recommend your child's school?

Share one unique aspect of your child's school and how it has positively impacted his or her growth.

Here are your responses:

Absolutely! It's mind boggling how the many different teachers and therapists collaborate together to help Sarala reach her full potential. With state-of-the-art equipment and many different therapies, they keep looking to add more and do what's best for our children. Sarala's teachers and therapists give us so much of their own time to discuss her progress and see what they can improve. SCHI is incredible!

* * *

My daughter Chana Leah attends SCHI. It is Gan Eden in this world! The staff in the classroom are so devoted to her growth in all areas of her development. There is nothing that goes unnoticed and she is so well taken care of. We are so thankful to Hashem that she is there!

* * *

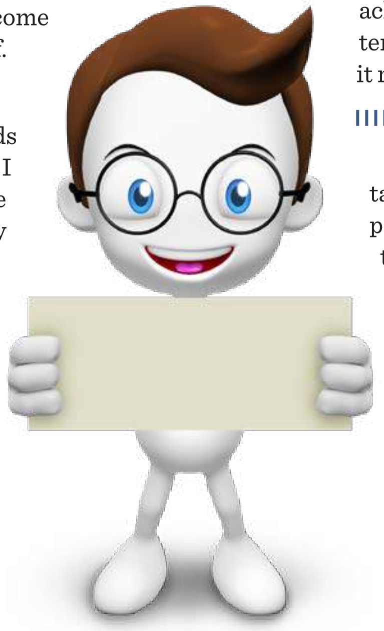
Bnos Ohr is an incredible place where they really push Pessy to reach her fullest potential, believing in her every step of the way. I can really see how much this support has helped her become more secure and confident in herself.

* * *

Definitely yes! My son attends L'gadel which is a class in Meirim. I find the level of individualized care that they have to be amazing! They do a lot of exercise outdoors. This helped Yossi tremendously, and BH he walks outside with much less assistance!

* * *

Miri attends Bais Rivka Rochel in Lakewood. It is absolutely amazing to see how committed her school is to each student's success. During our first meeting with the staff, they asked: "Imagine money wasn't an issue, and we had all the resources. What would Miri need to be successful here?" That question really showed how deeply they care about creating the best environment for each student to thrive in.



* * *

KJ School is always open to new ideas and receptive to suggestions from parents. They truly value and respect input from parents, creating an environment where collaboration and communication are key to the success of each child. Tovya is in great hands!

* * *

My daughter's school, situated within a medical and therapeutic facility, offers extensive enhancements. One great amenity is their pool, where Chaya Malky receives aquatic therapy sessions twice a week. The school painstakingly caters to the individual needs of each child rather than utilizing a one-size-fits-all approach. Each student receives her own academic program with detailed, personalized goals that are developed for the specific child, considering her unique capabilities. My daughter has grown tremendously since she's in Tiferes Mordechai, where each and every handpicked staff member really cares and works diligently to achieve the very best for our precious daughter. Nobody is there just for their paycheck and it really shines through.

* * *

What's unique about Bais Yaakov Elementary is that the administration is made up of people with true depth and pnimiyus. They truly 'walk the walk' of paying attention to the neshama, and because of that, they see beyond the exterior. They recognize Batsheva as a beautiful neshama they want to nurture and raise to be an eved Hashem. Another standout aspect is how seriously they take confidentiality. HIPAA laws are strictly followed, ensuring everything shared remains private, which creates a comfortable and secure environment for parents.

Eis Laasois School Age program is fully invested in each of their students. The entire school staff displays extraordinary and unmatched respect for and emotional understanding of every individual student. They have also created an outstanding classroom curriculum highlighted by a cutting edge literacy program. We wish them continued success!

* * *

Viznitz Monsey is an unbelievable school. Whenever I call to request a favor, the principal or secretary always responds the same way: "No different than any other girl, every child must thrive and grow in the school environment." It doesn't matter if they need to go above and beyond for one child, they do it with incredible dedication. They even emptied an office just so Esty could have a room for therapy, although it wasn't for scholastic reasons. They see it as their responsibility from 8:30 to 4:00 to make sure that every child has what they need.

* * *

Shaya attends the Henry Viscardi School. I totally recommend it for children with physical disabilities who are cognitively bright. The only drawback is it's not a Jewish school and it's far away. They teach the kids communication and regular material according to grade level so they don't stay in the same grade for a few years. Even though Shaya is nonverbal and hard to teach, they absolutely do an amazing job!

* * *

Absolutely! Perry is in mainstream HeadStart in Beis Ruchel Boro Park. The principal, who has her own special daughter, makes sure that teachers and shadows are all working together in an outstanding manner. They are so welcoming and try very hard to make it work.

* * *

I wish my son's old school would not have closed down. BY crown heights was really terrific with Shaindy Nathan as his Morah. I find it's more important for the individual staff in each classroom to be outstanding than the entire school...

* * *

Since Hinda Bracha began attending Yad Yisrael, she smiles a lot more, and we can tell she is extremely happy. Her PT, OT, speech, music and animal therapists are all doing whatever they can to make her better. They are especially devoted when it comes to weight bearing and put her in her gait trainer every single day. We can't thank them enough! ●

Cartoon Corner

"Keep staring... I might do a trick!"

info@vividcreations.co