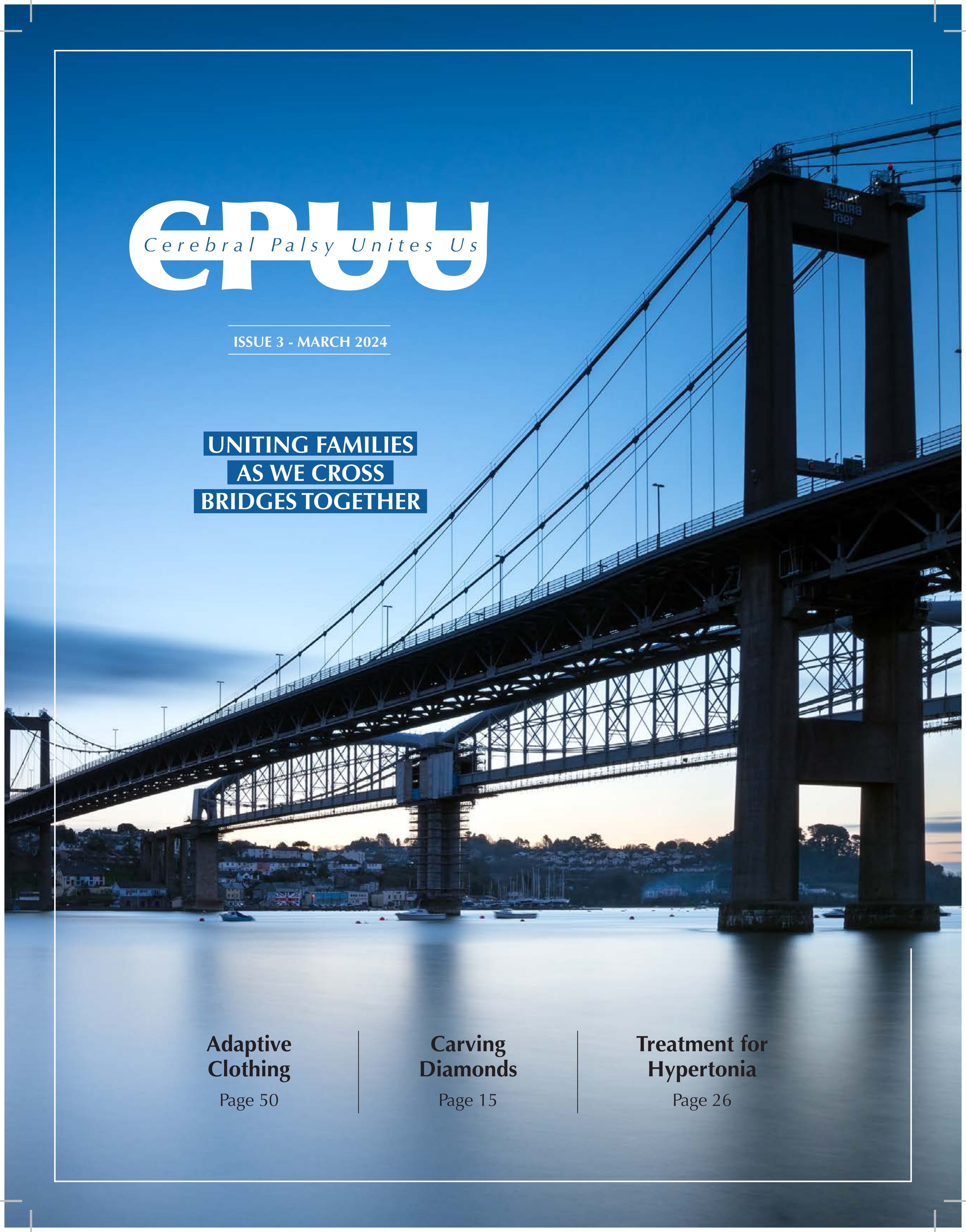

CPUU

Cerebral Palsy Unites Us

ISSUE 3 - MARCH 2024

UNITING FAMILIES AS WE CROSS BRIDGES TOGETHER

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Note: This magazine contains Divrei Torah.

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Editorial

Dear CPUU Families & Friends,

Welcome back to our third edition full of inspiring and beautiful articles and features! As we were gathering everything together, the term flexibility kept coming up. Flexibility plays a huge role in our lives, in the very physical sense, in our emotional and cognitive processes, and ultimately in our avodas Hashem.

Dr. Hurvitz, Shaindy Silber, and Sushi Zucker have provided extensive knowledge and information regarding spasticity, which is helpful for flexibility in individuals challenged with hypertonia. They offer helpful research and guidance on the different interventions and treatments used for hypertonia. Dr. Berkowitz delves into the cognitive domain and expounds on flexibility for individuals who need routine and structure to function in daily life. He offers insight and advice regarding changes that often come up. Dr. Berkowitz provides guidance for building flexibility and resilience in children as well as ourselves. We appreciate all the detailed and relevant contributions to our CPUU family.

Hashem gifts us with many ways to serve Him and grow in kirvas Elokim, closeness to Hashem. "עצת ה' היא תקום", His will prevails and we learn, change, and grow along with the challenges and gifts Hashem grants us, bringing us closer to Him. Our avodas Hashem requires a lot of flexibility, as we constantly grow with the help of our unique gifts. Rabbi Hershkowitz expounds on tefillah and Rabbi Langer elaborates on chesed for us, both showing how flexibility plays a role in these areas. Tefillah and chesed have the koach to help us and all of Klal Yisroel, especially during these trying times. We all daven and do tremendous chesed every single day, which brings us very close to Hashem and is a zechus for our brothers in Eretz Yisroel as well.

Enjoy Draizy Gross's incredible flexibility in all three areas which we mentioned above, as she shares her personal experience along with her simchas hachaim.

We appreciate everyone's assistance and contributions so much. Enjoy all the wonderful articles and features, as we Unite and Cross Bridges Together! ●

The Publishers

Inbox

Hi, one of my friends sent me the first issue of your magazine, and I really enjoyed it! Could you please send me a copy either an email or snail mail?
Thanks so much for all your hard work that goes into making the CPUU, it really speaks so much to me as a teenager living with cp.
CYC

I just want to share that I got a tremendous amount of chizuk from your magazine. Specifically, from the article by Rabbi Hershkowitz where he uses the example of putting tefillin on a child who may be indifferent to it. It hit the spot as we have invested much into putting on tefillin on our non-verbal autistic child and we never looked at it like that. We were doing it more for him to bring meaning to his life. I never thought that it brings a nachas ruach to Hashem!
Additionally, Rabbi Fishel Schachter says, there is no prouder moment in shamayim than when a person says, “Rebono Shel Olam! I don’t have to understand my matzav. I must believe that you put me here. You created me as I am”.
This is a theme I have mentioned again and again in my writing but without a source....
Thank you!! What chizuk!!
Fraydel Dickstein

Thank you for your wonderful publication. May you keep on inspiring your readers with your spot-on information and chizuk. The poem on page 39 of Issue #2, ‘The Most Beautiful Flower’, was written by Cheryl L. Costello-Forshey.
Hatzlacha!
Yitzchok’s Mom

This magazine is a masterpiece--very well written and visually pleasing. Hatzlochah!
Golda Turner
Beineinu

Hi, We are really looking forward to your next edition. The entire family enjoyed it immensely!
Chavy Frier

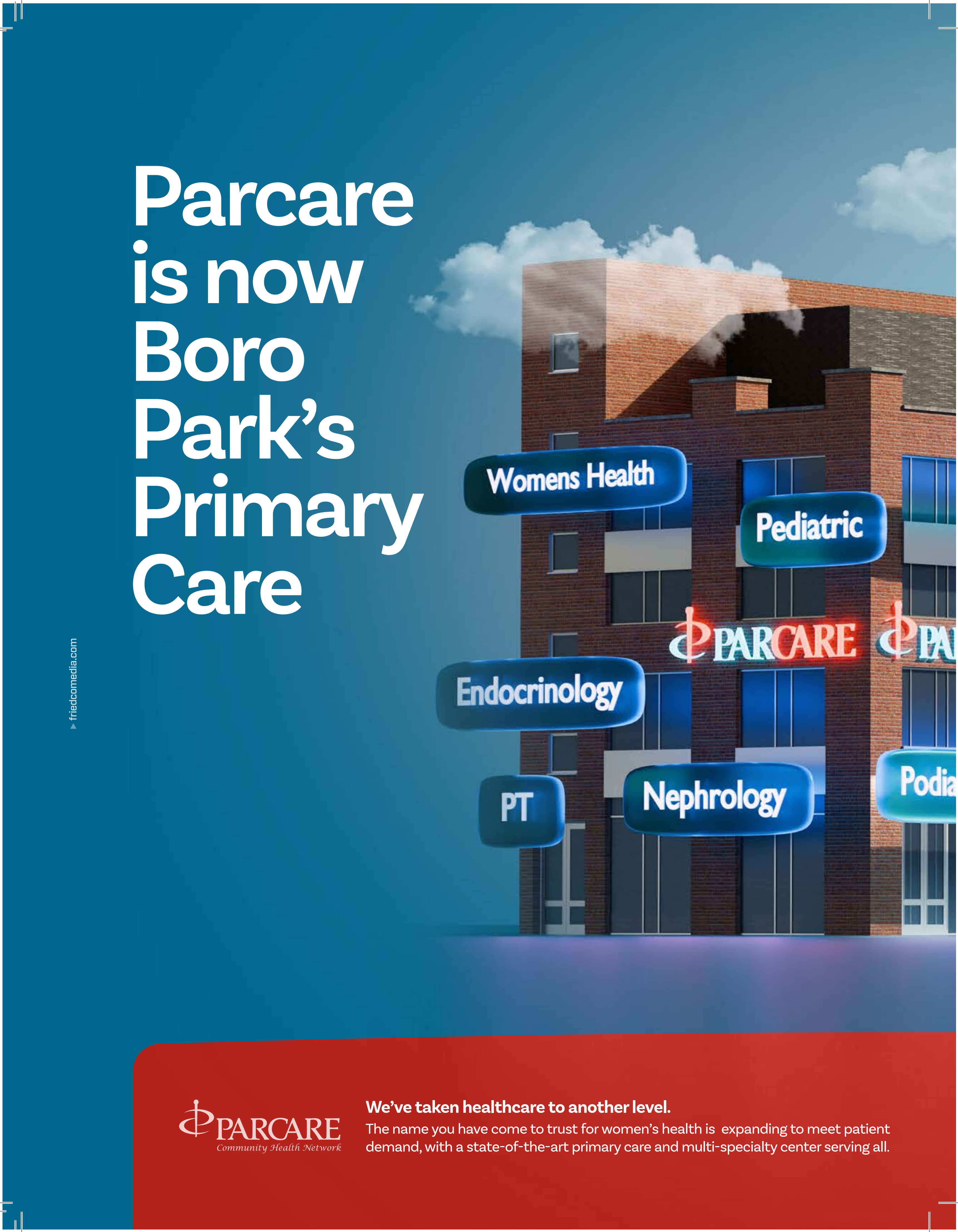
Hi, Is it possible to add me to your emailing list? I got the first issue from Mrs. Esther Nemetzky from Bina. I have a baby with a diagnosis of CP and epilepsy. Also is there a support system connected to the magazine?
Thank you so much.

Hi, It would be my pleasure to write something for your magazine. Perhaps an article about our life experiences, what we’ve been through and how we stayed strong. My triplets were preemies with Chavy the one doing well. Chavy was the healthiest of all, but Hashem had other plans, and Chavy is the one with CP. Our children therefore do not take life for granted!
My triplets are raving about you! Not so many of such real genuine people in today’s days, UNFORTUNATELY!
May it be with loads of Hatzlacha!
תזכה למצות!
All the best!
Nechama Fogiel

WOW! I have no words! You did an outstanding job again! Everything, the stories, the info, the pictures... Very professionally presented!
I was in camp with Esty, she is a delightful girl!
Hatzlacha, looking forward to the next issue!
F. Klinger

Hi, I have an adult adaptive bike that I’m looking to give away. The bike is in storage in Connecticut, if anyone can use it and has a way to transport it, you can reach me through CPUU Magazine.

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



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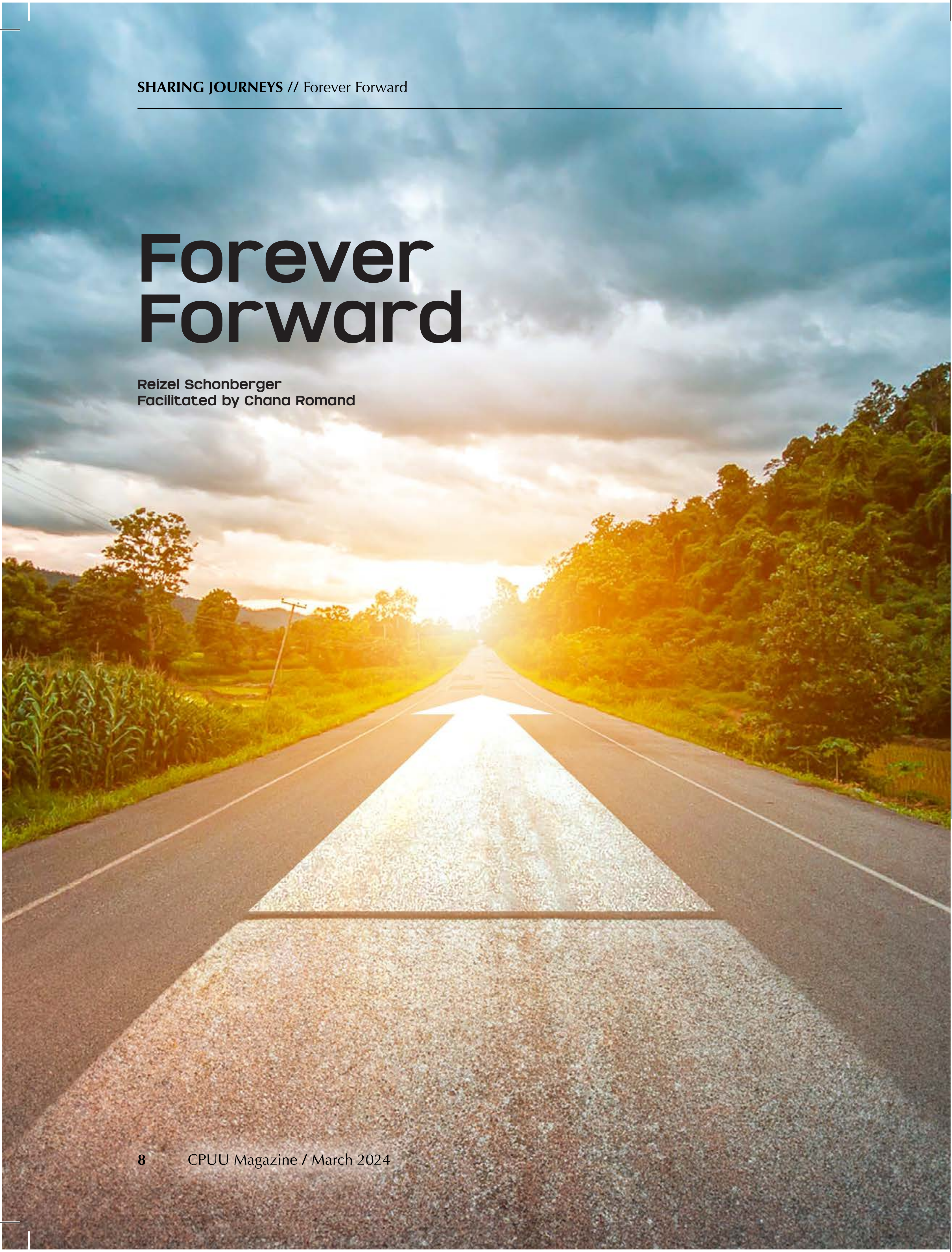
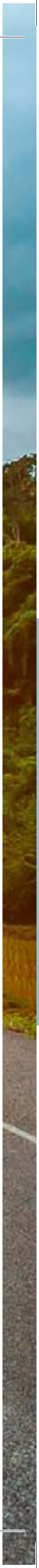
Forever Forward

Reizel Schonberger
Facilitated by Chana Romand





On the phone, her voice is unwavering and matter-of-fact. Reizel is a woman who has looked life in the eye and prevailed. She's strong, inspiring, and courageous.

My name is Reizel Schonberger. I am forty-six and have been married for 20 years. We reside in Monroe, NY.

I have Cerebral Palsy.

My condition was caused by a lack of oxygen when I was born. At that time the world for children with disabilities was a pretty murky place, much more so than it is today. My parents were pioneers; they pushed forward like Nachshon, forging a path for their daughter through a sea of ignorance and red tape.

I am the second child in a large family of mostly boys.

> **My parents were pioneers; they pushed forward like Nachshon, forging a path for their daughter through a sea of ignorance and red tape.**

My mother related that when I was a little girl she was pushing me in my stroller, while a younger sibling walked alongside me. A woman stopped her to helpfully ask why she was letting the younger one walk while the older one sat in the stroller! To the woman's credit, once she realized the situation, she apologized.

For the first five years of my life, my parents were able to arrange for me to receive services at home. After that, the government mandated that I receive services in a school setting. Left with no alternative, my parents had to enroll me in a public school in Goshen, NY. I traveled to Goshen every day for one school year, and then I was boruch Hashem accepted to attend the mainstream Bais Rachel school here in Monroe. The school principal came to our house to interview me and ensure I was on par cognitively and knew the Aleph-Beis, colors, etc. I was in!

I had a happy childhood despite all my physical challenges. Life was simple, and I was content to be home or in school with my friends. I sat through all my classes and listened to the lessons, although I did not take notes. I would try to arrange to have my physical therapy sessions when my class had hands-on projects. I viewed my PT sessions as a game; I enjoyed them because they helped me feel better.

I could not walk for the first nine years of my life. I was comfortable in my little wheelchair. When my parents talked about the possibility of surgery, I cried; I did not want to do it! But my parents understood that my life would improve with more opportunities, so in July, I had surgery.

After the surgery, the doctors put my legs into an A-frame, which meant a new type of wheelchair for me. I remember holding my 4-month-old sibling in my lap in my new wheelchair! My hospital stay lasted two months, and then I was in rehab until the following February. In rehab, I learned to walk with the support of a walker. During my months out of school, my mother arranged tutors for me to keep up with my schoolwork. Thanks to her efforts, I retained my grades and was never put back a class.

My courageous mother was proactive in my social-emotional development as well. When I was eleven years old, my parents took me to my first cousin's wedding. They sat me on a chair in middle of the hall so that I could watch the goings-on safely. I was okay with that, but my mother was upset that I did not have much opportunity to dance and interact with my cousins. She wrote a personal letter to each of her sisters and sisters-in-law, asking them to talk to their children about being more inclusive. Her efforts yielded results. That is how I got to know my many cousins, and until today, I truly am part of the family.

At home, everything felt normal; I was a part of our large and boisterous chevra. I remember once when my teenage brother's friend came to our house. He gave me the once-over and declared, "Your sister can't do anything."

My brother promptly shot back, "Don't you tell me that; I ask her all my questions. She knows what she's talking about!"

My ambition was to be as independent as possible. My mother was very busy with her large brood, and I could not depend on her for everything. That made it easier to achieve my goal. However, the older I got, the larger my equipment got, and the doorways of our home became an obstacle course. I attempted to convince my physical therapists to teach me how to get around with something smaller than a walker, but they pooh-poohed the notion, saying, “You’ll never do it!”

One day, I was assigned a new therapist. In preparation for our first session, she thoroughly read the report in my file. Her first question to me was, “What can I help you with? You’ve already achieved so much for someone with your diagnosis.” I said I wanted to get rid of my walker and learn to get around with something smaller. She replied, “I’m giving you two years.” Within a year, at seventeen, I was walking on crutches.

My path diverged sharply from that of my friends when I turned eighteen. We moved on from high school and entered the land called “shidduchim.” I watched my friends and siblings celebrate their engagements and weddings one after another while wondering, “When will my turn come?” The constant flow of engagements and weddings gradually slowed down, and the pain lessened somewhat.

> **I never gave up on my goals. If one person rebuffs me, I’ll try someone else. You can’t go backward; you must move forward in life.**

I consoled myself, knowing that my bashert would show up precisely at the right time. In fact, he could not possibly have made his appearance any earlier because he is six years younger than me! Our shidduch was suggested when I was twenty-five, and my husband was only nineteen. He also has CP, although in a different form.

Our shidduch process was unique. Our parents had to discuss all the practicalities of this potential match before we even met. How do the young people get around? Who will assist them with the everyday tasks of life? In fact, many shidduch suggestions failed to materialize because these questions could not be answered satisfactorily.

B’chasdei Hashem, my husband passed muster, and we announced our engagement. Everybody was so excited! My mother still has the letters of congratulations that my nephews from Canada sent us. We had a nine-month engagement, and it was barely enough time! My parents moved one flight up and renovated their previous apartment to suit our needs. We needed to order custom-made beds and navigate the numerous shops with my limited mobility.

We also found a kallah chair built atop a platform with wheels that someone had made for her daughter. It was perfect to use instead of a wheelchair, to keep me safe among the excited crowds. The chair was delivered about a month before our wedding, and my creative sisters-in-law decorated it all in white. Oh, was it a joyful wedding!

We are boruch Hashem married for over twenty years, and still living in our first apartment. We have a full-time aide to assist us with our needs. Besides managing the monumental challenge that is daily living, I am active in distributing the Sefer Chafetz Chaim in Yiddish, that my grandfather initially printed and we continue to publish. I handle the phone calls from retailers and private individuals who want to purchase the sefer.

I never gave up on my goals. If one person rebuffs me, I’ll try someone else. You can’t go backward; you must move forward in life.

Reizel should know. She stands at the forefront of a life of constantly pushing forward, always forward. ●

**Name changed to protect privacy*

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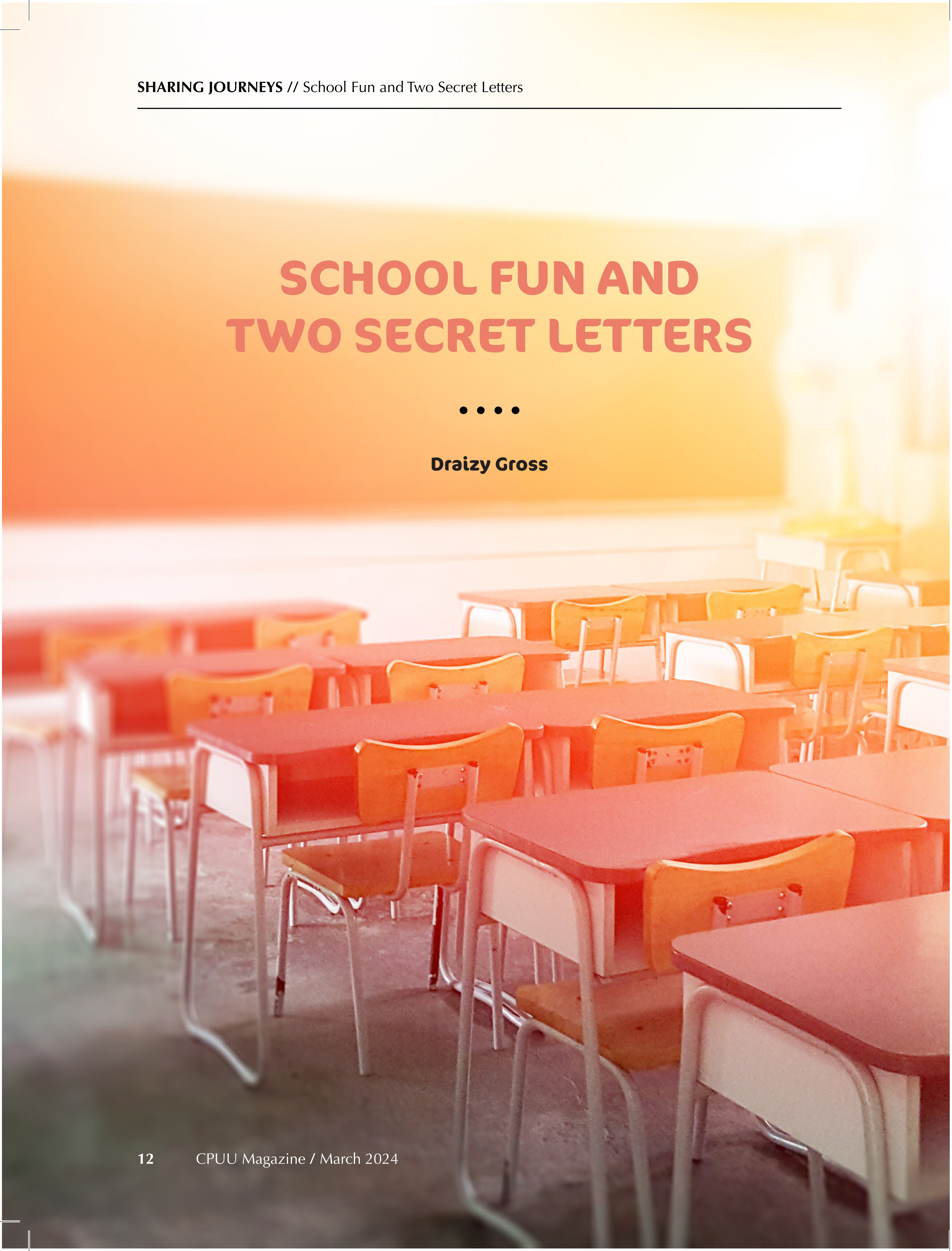

SCHOOL FUN AND TWO SECRET LETTERS

• • • •

Draizy Gross

Ask any teenager and they'll tell you that high school is the most fun; it's a ton of work, and a ton of laughter, too. For many girls, those four years are usually the most carefree and enjoyable times. For me, baruch Hashem, school was also the most amazing experience ever, yet one thing made it a huge challenge: CP! This two-letter diagnosis changed everything, and I mean EVERYTHING! Trying to juggle all my schoolwork, extra-curricular activities, and the secret two-letter condition was tough, but I took up the challenge and learned some extra lessons.

For me, baruch Hashem, school was also the most amazing experience ever, yet one thing made it a huge challenge: CP! This two-letter diagnosis changed everything, and I mean EVERYTHING!

I had to start my day early, very early. Which teenage girl gets up an hour before she has to leave for school? I did! There was no way to know what might happen as I tried to get ready. For example, I often hurt my gums while brushing my teeth. Buttoning my uniform shirt was always a hassle until I got every button through its correct hole. Tying my shoelaces? Extra fun! Those unwelcome tremors could really set me off my schedule. And breakfast, well that really depended on what was for breakfast and how much preparation was necessary. The more I rushed the more likely I was to spill my coffee, miss the cereal bowl, or end up with raw scrambled eggs on the floor. Then I had to get my coat on, fumble with the zipper, and walk around the corner to school. At least that part was easy. Living near the school has some benefits. But then I had to run up five flights of steps to my classroom.

Even though I had to work very hard, school itself was an absolute blast! The hardest part of school was taking notes; I never managed to write a complete set of notes for any class. That's what photocopies are for. I could have relied on copying all my notes, but my inner perfectionist would get frustrated when I couldn't keep up with the class. I would get distracted while writing and lose the lesson and the flow of the class. It took some time for me to finally give up writing notes entirely so that I could sit, listen, and take in the amazing lessons my teachers presented. Tests were a test on my nerves. Not because I wasn't sure of the course material, but because I was scared that I wouldn't have enough time to write everything down; and I had a lot to say and explain! I was constantly checking my watch and hoping the clock would stop for a little so that I could finish on time. I got more and more apprehensive as my classmates finished and left the classroom. Sometimes, I was given extra time out of class, or the teacher tested me orally. Even short quizzes took a toll on me. Writing was and always will be an enormous challenge for me.

Surprisingly, I enjoyed literature and writing class, not the actual writing part, but the creative and 'brainy' part. I was gifted with a very vivid imagination and loved getting all my thoughts onto paper. I stopped looking forward to one of my favorite classes because of my writing challenge; it was the same as taking notes. It was always a race against time, watching my friends complete their work, while I still had so much to write. I had all these wonderful ideas and the perfect outline in my mind, but sometimes, writing it all out in great detail wasn't worthwhile. My grades were sometimes lowered because I didn't explain something clearly. I often wished the paper would read my thoughts so the words would magically write themselves! It was frustrating when the bell rang, and all I had scratched out was one paragraph.

My solution was to take all my writing assignments home and type them all up: essays, stories, songs, and all other written work. Guess what? That gave me extra homework and screen time. Typing is definitely easier than writing, though it comes with its own struggles, but it worked! I was so lucky to have a scribe write for me for the regents.

Modulating my voice is a work in progress. By the time I reached high school, I was pretty happy with how I sounded. My friends could all understand me, and I also felt confident answering questions in class, but it came with a lot of effort and concentration. I'm still taking speech therapy! Therapy is amazing, but I still had to concentrate on using the correct techniques, breathing properly, refining my posture, and combining these all together in live conversation. On the first day of the school year, I was always edgy. Substitute teachers made me tense, too. I had to concentrate extra hard to make sure I was speaking clearly, and the teachers recognized what I was saying. I'm not shy at all; I just kept quiet when I didn't think I would be understood. This often happens in big crowds. I act shy sometimes just because I'm scared to talk. It can also get annoying when people have to ask me to repeat myself. But have no fear, I'm fortunate to have a great group of friends, and I always make sure that I am heard when necessary.

Lunchtime had its own routine. In my school, lunch was always served buffet style on long tables in the hallways. Most girls would help themselves to food and stand around eating and shmoozing. It was fun for them. For me, not so much. I had to concentrate fully on my plate and on the food. I was scared the tremors would make me drop food and create a mess 😊. Once I successfully filled my plate, I would make my way back to my seat in the classroom. There's no way I can hold my plate in one hand and eat with the other. So, I sat and ate like a mentch! But I didn't want to feel left out and be considered socially off, so I invited my friends to sit with me. That was sometimes so annoying because I didn't want to impose on girls. Soup on the lunch menu? Out of the question, that would never end well, and it was awkward to ask someone to serve me. Drinking from a cup was a big, huge no-no for me. I was not in the least bit interested in recreating Niagara Falls in school, so it was water bottles for me all the time. And napkins, lots of napkins to prevent and clean up the inevitable messes.

> **Overall, my high school years had many ups and downs, yet looking back at those four fantastic years, I'm filled with gratitude. Every test that came my way actually made me grow.**

Even the fun parts of school came with their own set of difficulties. First and foremost, I had speech, occupational, and physical therapy after school twice a week. These sessions took up a pretty nice chunk of my afternoons, so my homework and phone time was later; there were many long and late nights. It's not much of a problem for me; I'm a 'night owl.' Aren't most teenagers, anyway? When we had to stay late in school for projects, I would have to leave for my therapy session and then come back to school and catch up on the fun. I really enjoyed singing, but I was never in a school choir because I was too embarrassed to sing in public. When I was part of a dance, I had to work hard to catch up with the motions and keep my balance. If it was a song-dance, I just lip-synced the words and focused on the dance. Singing while dancing was way too much for me. (My singing eventually improved, and I slowly started singing in public!)

I truly loved the school matzav, but I was always conscious of what and how I was doing it all. Whether it was singing, dancing, props, cheering, arranging, etc. Whenever I felt uneasy about being involved in something, I stepped back and let others take care of what had to be done.

Overall, my high school years had many ups and downs, yet looking back at those four fantastic years, I'm filled with gratitude. Every test that came my way actually made me grow. I'm so thankful to Hashem for giving me so many abilities to get so far in life despite the hardships. I am so lucky because, at this point in my life, I can proudly say that I'm the giver, blessed with the awesome ability to work with children. Second, I'm so lucky to have the most encouraging parents ever. They were and are constantly by my side. I'm never alone, no matter how big or small the situation is. My fears and feelings are always their primary concern. Their devotion is beyond words. I'm so fortunate to have the most wonderful grandparents, who always show their love and care for me and all their other eineklach. My three siblings are the best! They are always ready to help. I am so blessed to have the greatest and yummiest family ever. I want to thank all my extended family and friends for giving me a chance and genuinely being there for me. ●

Carving Diamonds

Chaya Malky's Mother

For two years after I got married, I would lie in bed and imagine myself turning into a young mother, with all the excitement and stress that this new title brings. Often, I liked to skip ahead in my fantasy, and picture my child going and coming from school/cheder and then, later on, high school/yeshiva. I would imagine all the pleasures and stresses that would come along with these years, and I would let my thoughts fly on and on. Often I would have another thought. "Ribono Shel Olam, are You truly considering granting me a precious neshama of Yours to raise in this challenging world? Do You trust me in fulfilling this task of making a Yiddish kind into a loyal soldier in Your army?"

When this exciting day arrived, way sooner than expected, I got my answer very clearly! "Indeed, I trust you, my dear, not just with a 'typical' precious neshama; but far more than that. I took a neshama from a high place, very close to My kisei hakavod. One that has to do a very slight correction in this world, and therefore got the zechus to be wrapped in a guf that can't do any aveiros, so it will come back up whole and go straight up to the highest place where it belongs. This special neshama I chose, to give into your able hands. I'm sure you'll do great."

There was a king who owned a diamond whose beauty was hard to find. He enjoyed looking at it and holding it, appreciating its sheer beauty. One day, to his dismay, the king discovered a horrible scratch! The king was very annoyed, yet he would not allow anybody to scrape off even the smallest part of the stone in order to remove the scratch. He was not willing to let it lose even a single karat, which would thereby diminish its great value.

Many professionals came to view the stone, contemplating a cure for the flaw, with no success. Finally, one humble man offered to do the job. He asked for a week's time. When he returned and unwrapped his work, everyone stopped in awe. It was a true masterpiece! Instead of scraping off pieces of valuable diamond to remove the scratch, the gemcutter had taken this very flaw and made it look like a stem, cutting his way up, creating a beautiful rose. Now, the diamond had tripled in value! Not only was it a brilliant stone, but it had a magnificent design of a flower engraved in it.

Upon receiving our delicious bundle, we very soon discovered her "flaw". We will indeed do our utmost to carve this "scratch" into a beautiful rose.

Ribono Shel Olam, please give us the koach to do it right, אמן. ●

Sunny Side Up with Queen Pineapple

Esty Kay

What do you think of when you think of pineapples? Pineapple smoothies, grilled pineapple at family barbecues, tingling and burning on your tongue when you eat pineapple. Anything else? Well, I'm sure you weren't thinking queens! Queens? Yup, queens! Now, what is the connection between pineapples and royalty? Nothing besides for a queen eating a pineapple 🙃. But there's another commonality. Me! Introducing Queen Pineapple. Yes, that's me, Queen Pineapple. (My Israeli friends call me אננס מלכה.)

So now you're curious: why do my friends call me Queen Pineapple? You think it's because I like pineapple, right? No, not really, but we can save the debate of whether I like pineapples for another time. So, let me tell you how this whole thing started. One of my friends called me The Queen, and she said royalty doesn't hesitate to ask people to do things for them. It's their right; it's called 'getting royal treatment.' If I need help or do things differently, that's okay. It's my privilege; I'm The Queen. Well, that summer, I was in 'Bunk Pineapple,' and being The Queen, I automatically became Queen Pineapple.

Sometimes, being a queen can be quite a challenge. You know, being royal isn't just a privilege; it's also a responsibility. My responsibility is to stay positive and find the good in every day as much as I can. There's work involved to keep the title (no queen wants to lose her crown). So, I put in the work.

Believe in the people who believe in you. They are the bridge to your dreams!

The Pineapple Status
9089101957

As long as I can remember, I can usually come up with humorous or inspirational quotes. I like to write them down and hang them on the walls in school or camp so other people (and me) would be motivated and infused with some positive pineapple energy throughout the day. This helped me when I couldn't participate in some activity or was just feeling down for whatever reason. Reading the quotes could usually switch my perspective. I mean, having a bad day isn't the same as a bad life; I can get through this one day, I can do it!! I noticed that other people were also impacted positively (in pineapple style). It brightened their day and they smiled when they walked into my room.

And so began the 'Quote of the Day'. Every day, I added one quote, which eventually turned into hundreds of quotes. It became a thing. By the end of the school year or camp season, there were tons of quotes papering the walls (pun intended) of my therapy room and my bunkhouse in camp.

This went on for quite a few years, and after I graduated high school, I started a WhatsApp group called 'The Sunny Side Up.' My aim was to post inspirational quotes for people dealing with different disabilities or chronic illnesses. Eventually, the group petered out, but there still is the 'Queen Pineapple's Pineapple WhatsApp Status,' where I still post Queen Pineapple's Quotable Quotes of the Day and periodically send inspirational quotes.

So now you know how I got my name and the connection between queens and pineapples. Whether I like pineapples or not is not up for discussion. The End😀.

So here I am, a few years and many quotes later. My closing message to you all is:

- YOU can do anything you set your mind to.
- It's the little things that make the biggest difference.
- A kind word can go a long way!

Just a word of advice for anyone out there without a disability. Don't send quotes to your friends too often. Send them a quote occasionally, but don't bombard them unless you know they like and appreciate them. Like with any text, use good judgment because you never really know how someone will take it. Take their lead, ask them, and they'll tell you if it's good (or not). But that's just my royal opinion on this, and everyone's different. And take it from me, 'small acts of kindness go a long way.'

I am wishing you the sweetest day ever! ●

For questions, comments, or to join the Pineapple Status, I can be contacted through CPUU Magazine.

The Bigger Picture

H. Gross

Birthdays are a great opportunity for reflecting on the past year, expressing gratitude and hope for the future. It's Tovya's eighth birthday. My adorable 8-year-old son has a lively, happy temperament, despite his physical limitations. He has microcephaly, cerebral palsy, and cortical visual impairment (CVI). He is non-verbal but can express himself with happy sounds and giggles, and communicates via his Tobii Dynavox (eye gaze device). He is our youngest child, with doting older brothers and sisters who take an active role in his care.

After he was born, I couldn't imagine how my family would manage. When I met a friend whose husband has ALS, she gave me chizuk and predicted that my children would grow through the challenge. My children grew; we all did! They became more sensitive to others, especially to those with special needs.

We were very fortunate; Tovya was not a 'hospital baby.' He came home right after birth and was not hospitalized at all during his first years boruch Hashem. Most children with microcephaly have frequent seizures, but Tovya did not have any.

Tovya's favorite pastime is food; he loves to eat and is very food-motivated. I would spend a lot of time preparing his favorite foods and then pack them up with several bibs to take to school. I was surprised when his teacher expressed how she was amazed that he was fed by mouth. I thought, why not? How else should he eat? Another parent told me that her child eats for fun; he receives nutrition via a gastric tube (G-tube). Not my son, I thought; he eats and takes all his medication by mouth. Tovya spent so much time eating that it probably took away from his therapy time.

Tovya's school and therapy appointments are quite a distance from home. A lot of time is spent traveling on the road, but we learned that life is a journey, and this is just part of it. We must remember that Hashem programs the GPS of our lives, guiding us to our best personal direction.

Tovya had his first seizure when he was four years old. His teacher mentioned that he would sometimes appear to be spaced out and lose focus. It was time to consult a neurologist, who put Tovya on anti-seizure medication, and we started a new chapter in our lives.

The seizures were very frightening, especially the fear that came along with it, but gradually we got used to them, and can now even joke about it. We got used to the syringes that we used to give Tovya his medications; they were everywhere. Tovya loved chewing on them, and we once ran out of usable syringes and had to borrow one from a neighbor. Now I make sure we have plenty of syringes, we have a collection of syringes in all shapes and sizes; we can open a gemach.

At first, the medication seemed to work, and he had fewer seizures, but after a while, he began to have more seizures, and we had to increase the dose of his medication. The human brain is so very complex, and seizures are so tricky. Medical professionals have more questions than answers regarding the brain, but we were told that the seizures indicate brain growth and development. This knowledge helped me shift my fear, I started developing a more positive attitude towards the seizures. More significantly, I was struck by a remarkable idea: Tovya is non-verbal and he has no way of telling us that he is not feeling okay; the seizures are really a gift because they give us an idea of what's going on with him.

The spring and summer of 2022 were hard. Tovya wasn't his usual smiley, perky self and was having a lot of seizures, even with new medication. He was moving around less when he was on the floor and he was also a lot quieter, not expressing himself as much as he usually did. We blamed everything on the seizures and medication. I started tracking the seizures to see if there was a pattern. This is a typical week of tracking:

Sunday: 6 AM, seizure
Monday: 6 AM, seizure. 8 AM, seizure
Tuesday: 8 AM, seizure
Wednesday: No seizure, boruch Hashem
Thursday: 2 seizures
Friday: 7:30 PM, seizure
Shabbos: No seizure, boruch Hashem

After the summer, Tovya improved somewhat. I had been looking for a nutritionist to help me manage Tovya's diet, particularly with his calorie intake. Many people recommended Elisheva Braunstein, I managed to reach her, and she started guiding me with Tovya's diet. She encouraged me to supplement him with Kate Farms formula. Elisheva is one of Hashem's special messengers; she is available on the phone and is supportive in many situations.

My children grew; we all did! They became more sensitive to others, especially to those with special needs.

By Chanuka, Tovya was even better. His therapist reported that he was more active. We noticed he was more alert at home too. My nephew was getting married in Eretz Yisroel, and I wished I could go. I desperately needed a break, and a trip to Eretz Yisroel and a family simcha seemed to be just what I needed. With Elisheva's support and guidance, we were able to leave Tovya with a qualified babysitter and get that much needed break.

Our trip to Eretz Yisroel was a dream come true. The wedding was beautiful, and the weather was mild. We enjoyed the sunny, blue skies; Hashem sent us perfect weather while we were there. I kept in touch with Tovya's babysitter a few times a day, and she reported that he was doing very well and did not have any seizures the entire time we were away. The day we got back from Eretz Yisroel, I got a telephone call from Tovya's school; he had a seizure! Could it be that he sensed he was going home after school, and it triggered a seizure?

Tovya had been needing an inpatient EEG (electroencephalogram, a test that measures brain activity) for a while, and I kept postponing it. I wanted to get an appointment at the beginning of the week so we would not have to stay in the hospital over Shabbos. But by now, it was very urgent to get the EEG done, so we took Tovya to the emergency room and he was admitted to the hospital.

This was on a Tuesday, and we figured we would stay one or two nights and definitely be at home before Shabbos. But while we were waiting for the EEG, Tovya had a few seizures, and he was given strong drugs to stop them. When everything calmed down a little bit, a nurse checked his vitals, and his temperature was dangerously low, about 94. She was sure the thermometer was broken and tried another one but got the same result. Tovya was rushed to the PICU, where he could be monitored closely. They used a special warming blanket called a 'Bear Hugger' to help regulate his body temperature. Blood test results showed a high white blood cell count, which indicates infection, and he was given strong antibiotics. He was very sleepy from all the medication, and once the seizures stopped, he was taken off his original anti-seizure meds and only given the new one and the antibiotics.

The next day, a speech pathologist came to assess Tovya and started questioning me about his eating and if he aspirated. I was getting annoyed. He was admitted to the hospital for an EEG; why is a speech pathologist getting involved and asking all sorts of questions? The next day, she was back. Tovya was more alert and she observed me feeding him; she was pleased with what she saw but wanted to administer a full swallow study. She was making me nervous because Tovya was still quite lethargic and not eating as much as usual.

Based on her observation, the hospital would not discharge Tovya without a swallow test. I was desperate to be home for Shabbos, so I agreed to the test. Tovya failed the swallow test, and on Shabbos, the nurses inserted a nasogastric tube (NG tube, feeding through the nose). Tovya was lethargic and cranky, and I was not happy at all.

Over the next few days, Tovya started feeling better and was much more alert. On Tuesday, another swallow study was done, this time with thickened liquids, and he passed, boruch Hashem! We were ecstatic. I was given careful instructions on how to feed Tovya and make sure he gets enough nutrition. Then they offered to give him a gastric tube. I was very adamant about it; Tovya could eat, and he did not need the G-tube. No thanks, no way!

I was horrified to see the word 'malnutrition' on the discharge papers. We were so dedicated, spent a lot of time feeding him, and were careful to do everything right. Malnutrition seemed way too harsh, like we were not good parents. We settled in at home, but after a few days, Tovya was very sleepy again and not adjusting to the new medication.

One morning, I was making my way to the hospital again, this time for a simcha. I was going to visit my daughter who had just given birth to her first baby! As I got closer to the hospital, a nurse from the neurologist's office called with the results of Tovya's most recent blood test. She said to lower the dosage right away and come back for more bloodwork. Tovya was in school, I was busy with the new mother and baby, and it was a few days before Purim! What next?

I was exhausted. I was waking up to feed a newborn and waking up Tovya to feed him, too. He needed nutrition, electrolytes, and medicine. We finally got the blood test done, and Tovya's blood numbers were way, way above the normal range. We had to stop the medication completely, immediately! And he needed yet another blood test. Now we had to decide if the blood test would be done on an inpatient or outpatient basis. We decided to have the blood tests done in an outpatient lab because there was so much going on in our house, and it was a few days before Purim.

On Purim, I stayed home with Tovya while my husband took the rest of the family to visit his parents in Brooklyn. Tovya and I sat on the couch, and I tried to keep him warm and his body temperature stable. I was anxious and kept checking his temperature and looking for signs of dehydration. I also called our pediatrician, and he ordered chest X-rays. All the medication Tovya was taking was slowing down his system, and the doctor was concerned it could lead to pneumonia. His system was so sluggish that his body temperature dropped considerably, and we rushed him to the hospital again. During this period of antibiotics, I did not protest when the doctors inserted the NG tube. I realized how weak Tovya was and knew it was the best way for him to get the necessary nutrition and calories.

Gradually, the toxic levels of medication in his system lessened, and Tovya started to feel better. He started chest PT, and we also used the chest vest and cough assist machine. This time, the speech pathologist wanted to observe him over the next several days. He was very weak, he hadn't eaten in a few days, and his body needed to heal, so she allowed him to eat five spoonfuls of food at a time. Not one drop more.

We were so exhausted and just wanted to be home with my family and take care of my daughter and her new baby. The only way they would let Tovya leave was with an NG tube and pump. I didn't want the tube, but just to accelerate his discharge I agreed. It was a full week before we could go home. We had to wait for the feeding tube supplies to be sent to our house, and I learned how to use the pump.

Tovya failed another swallow study. He really was not eating well, and I thought some extra feeding therapy on top of what he was getting in school would be beneficial. I finally reached Esti Soloveitchik, an excellent feeding therapist I had been trying to get to for a while. She agreed to work with Tovya when she had a cancellation, and eventually, he was given a permanent slot on her schedule. Esti is nothing short of a miracle worker! She suggested we work with Mari, a breathing specialist, and Mimi Seif, a physical therapist who specializes in MNRI, TMR, and other modalities. Mimi taught me the MNRI seizure protocol, which is very, very effective for Tovya. For some time, I had been wondering if MNRI would be helpful for Tovya; now Hashem sent us the right people at the right time.

> I found that when we are surrounded with positive people, and positivity, it makes a huge difference!

Tovya was recovering; his appetite increased, and he was eating so well that by Pesach, we stopped using the NG tube. I shoved the tube and the pump into the back of a closet and canceled the next shipment of supplies. The medical supply company wanted me to return the pump, but a friend discouraged me. She also has a special needs child and convinced me to keep the pump. Our pediatrician was encouraging us to put in the G-tube as a backup, just in case. I didn't want to hear about it; Tovya was doing well, and it was all behind us. But I kept the pump anyway.

After Pesach, Tovya had a few more seizures and was lethargic again. A chest x-ray came back clear, so I called his neurologist. Again, his medication dose was increased, and we kept checking his blood levels and adjusted the dosage accordingly. There was not much improvement, and on top of all this, my next daughter was a kallah. The wedding was scheduled for the end of August; there was so much more to take care of now.

One day at school, Tovya was so sleepy his teachers couldn't wake him up. His white blood cell count was dangerously low, and Hatzolah rushed him to Westchester Medical Center. He had pneumonia again; he needed antibiotics to fight the infection, and the Bear Hugger and a warm hat to stabilize his body temperature. This was on Monday, and Shavuos was on Thursday; if Tovya would pass a swallow study, there was a possibility that we'd be home for Yom Tov. He failed the study. I was so desperate I actually begged for the NG tube. Since I had all the equipment at home, he was discharged, and we arrived home very close to the z'man.

It was wonderful to be home for Yom Tov, but it wasn't very good for Tovya; he was doing poorly, and his body temperature kept fluctuating drastically. It was a scary and stressful time for us. We returned to our pediatrician, who was very upset; he claimed that Tovya was hospitalized too frequently, and the seizures had to be controlled. We also had to figure out why he was getting infections and why his body temperature kept fluctuating. He emphasized how crucial it was to find the cause of the problem very quickly!

I had set an appointment with an excellent pulmonologist, Dr. Kazachkov, before Tovya was sent to the hospital. I had almost forgotten about it, and it was just what we needed right then. Dr. Kazachkov ordered a bronchoscopy, an inpatient procedure that tests the lungs and bronchial tubes (airways in the lungs). He wanted Tovya on the NG tube until he was completely well, and before he tried eating by mouth again. I quickly had to learn how to manage the apparatus. I am so grateful to the woman who taught me the technicalities and a whole new vocabulary; I became quite an expert! The bronchoscopy went fairly well, and the doctor allowed Tovya to eat a few spoonfuls every day under the supervision of a feeding therapist.

Tovya continued to get better, but the doctors insisted on replacing the NG tube with the permanent G-tube.

As Tovya was recovering and I had to focus on my daughter's upcoming wedding, I put all G-tube thoughts out of my mind. But I knew the G-tube was inevitable. Tovya had been eating well for a few years; thinking of him on a G-tube made me feel like a failing parent.

Intellectually I know I am not a failure.

As we gradually adjusted to and accepted the G-tube, I realized the many benefits that came with it. We no longer had to wake him up to feed him and give his medication.

It's Tovya's eighth birthday, and we have everything to be grateful for. Yet, very often, we spend a lot of time and effort to get what we want because we are convinced it's good for us, it's what we need, and we keep going in circles. When we let go and focus on confidence in the concept that whatever Hashem does is tailor-made for our personal journey of growth, and let Him take charge, everything falls neatly into place.

For a few years, I worked around the clock to make sure things worked out to my satisfaction. Then I realized that I had to give up my will for Hashem's will. When I finally did that, we got a gift, a new child! Since Tovya has a G-tube he's had fewer seizures, his body temperature is stable, he found his voice, is moving a lot more and gained weight! Best of all, his bubbly personality is back; he's full of energy and excitement. He still loves to eat and gets sweet treats occasionally, although we are still working on getting him to eat even more.

The journey to Tovya's eighth birthday was very challenging, yet I can't imagine my life or my family without Tovya; he enriches our lives in so many ways. Mostly, we learned to be grateful for everything, especially the challenges. We also learned to appreciate the typical milestones of our grandchildren, which we took for granted. Additionally, I found that when we are surrounded with positive people, and positivity, it makes a huge difference! When we recognize that Hashem led us through all these ups and downs, we can be hopeful and confident that the future will be good, and we can look forward to more birthdays and more miracles. ●

I can be contacted through CPUU Magazine.

REAL QUESTIONS *REAL ANSWERS*

Shoshana Levin, OTR/L

Q My child usually jerks when I do mouth massaging and tooth brushing with her. Where does that come from, and what would be the best way to help my child tolerate and be more comfortable with tooth brushing and face/mouth massaging?

A Thank you for your question! Oral care and health is so important for all children, especially those with cerebral palsy. There are many reasons why this is the case. Firstly, children with CP tend to have increased gastroesophageal reflex (GERD), which can cause teeth erosion from the resultant acid reflux. Excessive drooling may also increase dental and oral concerns. Other issues arise from the motor difficulties associated with CP. For example, when a caregiver softens food for a child, the sticky and softened texture may stick to the teeth more than regular food, causing teeth to decay. Additionally, children who have difficulty with sucking, chewing, and swallowing may eventually present with malnutrition, affecting oral health. All this means to say is that proper dental and oral hygiene is crucial!

Now to your question. Jerking and stiffness in the jaw and mouth is common in children with atypical tone. If a child has irregular muscle tone in the body, chances are it will also present itself in the mouth, which has many large and small muscles. Additionally, the lack of exposure to varied sensory experiences in the mouth may also cause jerking. Imagine touching sandpaper or light feathers. Your body is generally unfamiliar with the texture and may react by avoiding or slightly pushing back from the novel stimuli. This is similar to how someone who hasn't experienced a rich variety of textures in their mouth would react to vibration or tooth brushing. The mouth is arguably the most sensitive part of the body. Our lips have over one million nerve endings. Now that we know this information, we can better understand why we react more strongly in the mouth than in any other area of the body.

A child's postural alignment and control can also significantly impact oral care and feeding. Oftentimes, children with cerebral palsy have a forward gliding of the head and neck, which can cause misalignment of the jaw. This impacts the child's pallet, the Temporomandibular Jaw, (TMJ), and it can cause misalignment of the mouth. All these things impact a child's ability to effectively chew, swallow, and tolerate various sensory stimuli in the body.

Armed with this information, we can now determine what is the best way to desensitize and regulate the oral and facial areas. In this way, we can effectively clean and take care of our children's oral hygiene, depending on the source of their concerns. As always, these are general guidelines and ideas, and more specific interventions should be discussed with your child's occupational and/or speech therapist.

1. Postural alignment is crucial! Look at how your child is seated when eating and engaging in oral tasks. Try to get a forward pelvic tilt if possible, a straight back with squared shoulders, and a head and neck that is properly aligned with the shoulders and rib cage. This will help to create the best possible setup for oral and sensory activities.

2. Start with the outer oral muscles first. It's a good idea to start off with something more easily tolerated, and gradually work your way up to the harder to access and harder to tolerate areas. This gives the child time to adjust. Their sensory systems can then better orient to the new input. Provide input to the chin, cheeks, and eventually to the lip area as tolerated.

3. Experiment with different textures and materials. Your child may tolerate a vibrating toothbrush or or a Z-Vibe vibratory device right away, or you may need to start more low tech. Examples of textured, not as stimulating materials can be a wet paper towel, a wash cloth, or firm, deep pressure from your hands on the face, going from the ears along the jaw to the chin. Instead of sideswiping drool, try using a towel or washcloth with a richer texture, and provide purposeful strokes to your child's face to maximize the sensory experience and increase lip closure. Introducing various textures of food can also help desensitize the mouth. Depending on what your child can safely ingest, providing hard and crunchy vs soft and mushy foods is another great way to incorporate desensitization into everyday routines.

4. Look at the equipment you are using. For feeding, experiment with different sizes and types of spoons and utensils. Find something that will fit in your child's mouth and will also provide more feedback to the tongue and inner oral area. There are many on the market, including metal spoons, textured spoons, and spoons with feedback such as the chewy spoon. Look at the shape of the spoon as well. For oral care, the same rule applies. Find a toothbrush that is age appropriate and has variety in bristles.

5. Start off slow. Your child may only tolerate a few seconds initially, and that's okay. By staying consistent in your feeding protocol, children will hopefully tolerate more with a gradual approach.

Again, these are some general ideas that can be further explored with your child's clinical team.

Hatzlacha!

Shoshana Levin, OTR/L ●

Do you have a question for Shoshana?
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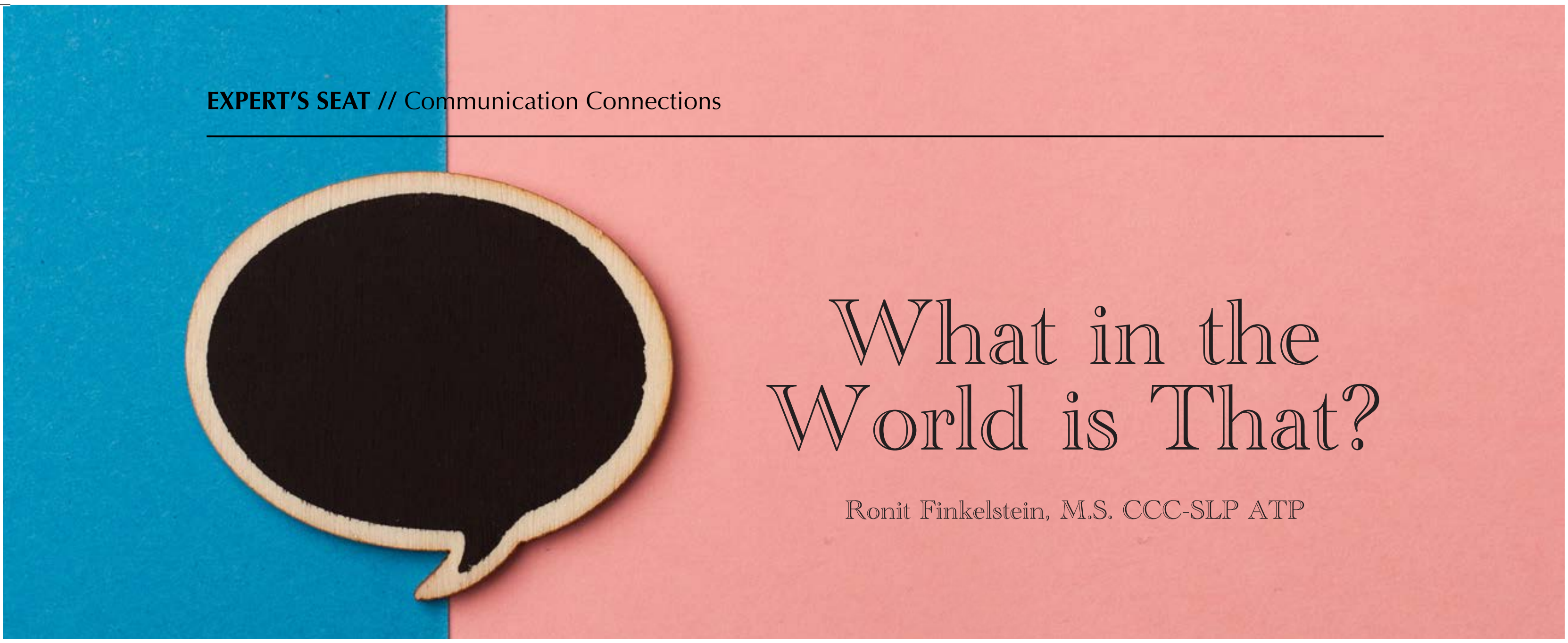

What in the World is That?

Ronit Finkelstein, M.S. CCC-SLP ATP

Hopefully by now, everyone has a clearer picture in their mind of how using the best type of communication tool with the right vocabulary makes all the difference in the world to a non-verbal communicator. Now comes the confusing part. When choosing a communication tool, there are many terms that are often used interchangeably. These terms however, do not mean the same things. Here is a rundown of some of the terms as well as descriptions/examples of each. Hopefully this will assist in clarifying the differences so that your decision making process is a bit easier.

Unaided vs Aided AAC

Unaided AAC:

This is any type of communication that a person can do with their own body and includes facial expressions, gestures, body language, and sign language. These are all methods of Augmentative (can help/support) Alternative (can replace) Communication.

Aided AAC:

This is any type of communication that needs external help and can be either high tech or low tech.

High tech vs Low tech devices

High tech devices are speech-generating devices with touch screens, scanning, head mouse, or eye-tracking technology that have dynamic display. They are set up so that touching one button can either speak, lead you to a new page (navigate), or speak and navigate.

Low tech devices can be communication boards with symbols or pictures. They can also have simple speech generating options with anywhere from 1-32 button/icons on them. An example of this is a Go Talk 9.

Dedicated vs non dedicated

Dedicated vs non dedicated device:

Insurance will only pay for something that will be used solely for communication purposes and not for gaming/watching/shopping. A dedicated device is one that is only used for communication and can be facilitated in two ways 1) Setting up the device so that the only thing on it is the communication program or 2) locking or blocking other apps on the device. An iPad can be set up in this way.

Hardware vs Software vs Apps

Hardware:

This is the frame/packaging for your communication program. You can think of it as if you are creating your own new laptop. First you choose the shell or frame and then you load it up with programs or software. Most manufacturers base their devices on premade tablets. The main companies that produce communication devices are Tobii Dynavox, PRC-Saltillo, Smartbox, Attainment Company, and Enabling Devices. Some of these companies produce low tech devices, while most produce high tech devices. Below is a listing of the various companies with a listing of the devices they offer.

Tobii Dynavox devices include: The **T series** (comes in 3 different sizes leading to their names T7, T10, and T15) and the **I series** (can be controlled through eye gaze and includes the I-10, the I-13, and the I-16). They also produce the **TD Pilot**. the **SC Tablet**, and the **SC mini**.

PRC (Prentke Romich Company) devices include Accent 1400, Accent 1000, Accent 800, and PRiO-mini.

Saltillo devices include NovaChat 5, NovaChat 8, and NovaChat 10.

Smartbox devices include GridPad 10, 12, and 15 and TouchPad

Attainment Company common devices include Go Talk 4, 9, 20, and 32 as well as Talker 24 and Big Button.

Enabling Devices common devices include Basic Talk 4, Cheap Talk 4, 6, or 8, 32 Message Communicator, 4-Level Communicator, 7-Level Communicator, Communication Builder, Logan ProxTalker, and Talkables.

<u>Software:</u>

These are the programs that you load or that come preloaded on your device.

Tobii Dynavox makes Communicator 5 and Snap.
PRC makes Words for Life, Essence, and Unity.
Saltillo makes Nova chat.
Smartbox makes Grid3.
Attainment Company makes Go Talk

<u>APPS:</u>

In addition to devices with specific software, there are some companies that have developed apps. These are mostly for Apple products but also used for Android devices. These apps can be purchased directly by a family for a preowned iPad or tablet. They can also be gotten after an evaluation and approval from Medicaid/insurance (sometimes only the app will be paid for and not the device). For school age children, the Board of Education will conduct an evaluation and provide the child with a device with apps on it.

Tobii Dynavox makes Snap and Sonoflex
PRC makes Lamp Word for Life
Saltillo makes Touchchat
Smartbox makes Grid3.
Attainment Company makes Go Talk
Assistiveware makes Proloquo and Proloquo2go
Therapy Box makes Predictable and Scene & Heard.

<u>More APPS:</u>

Other apps include SayIt!, CoreVoice, Talk Tablet Pro, Avaz, and Speak for Yourself, among others.

Whew! Take a deep breath! You made it through to the end!

You may be thinking, “How am I ever going to remember all this?” The good news is that you don’t need to remember it. You can keep this as a reference guide and pull it out as needed. Now if someone says “Oh my child uses a Tobii,” you will know enough to ask “Is that a device, a program or an app?”

Many of these programs and apps come with more than one vocabulary choice, but that is a whole other topic. (Hint: for the next issue.) ●

TREATMENT FOR HYPERTONIA

Edward A. Hurvitz, MD

Hypertonia, which includes spasticity and dystonia, is a common problem in cerebral palsy (CP), affecting over 90% of individuals diagnosed with CP. Spasticity is increased resistance in the muscle to movement of a joint, and dystonia is increased muscle tone accompanied by twisting, uncontrolled movements. Many people with CP have a mix of these two problems.

Spasticity is present in anyone who has an injury, sickness or malformation of the central nervous system, which is the brain and the spinal cord. When the central nervous system is not controlling the body as it should, the body reacts by sending too many uncontrolled signals to the muscles, leading to muscles that are in constant contraction, as well as increased reflexes, spasms, and shaking of the limbs. Along with CP, it is common in stroke, spinal cord and brain injury, multiple sclerosis, and other neurologic problems.

People with spasticity will have a constant tightness of their muscles, which interferes with the ability to control the body and coordinate movements. This high tone or tightness prevents the person, or their caregiver/therapist, from moving the joints through their full range of motion. It can lead to pain, joint dislocation and contractures of the joints, as well as interfere with daily activities such as dressing and bathing. Treatment for hypertonia starts with physical therapy, including stretching and strengthening. Bracing can be helpful by placing joints in functional positions, to counteract the effects of hypertonia. There are several medical interventions that are used to treat hypertonia, including medications, injections, orthopedic surgeries and neurosurgeries.

Medications for hypertonia work on different parts of the nervous system (or the muscles) to block some of the messages coming from the nervous system to the muscles, or by increasing the body's natural blockers. The effects of the medication are therefore felt all over the body, leading to decreased spasticity in all of the muscles. This will allow more freedom of movement. It also eases caregiving. Spastic legs make toileting care difficult, and spastic arms interfere with dressing. When someone has all of these issues throughout their body, medications can be a good choice. However, side effects must be considered.

There are several options. The most common include:

-Baclofen (Lioresal) this is often the first medication physicians try. It can be very effective in reducing tone and allowing more freedom of movement. It is taken two to four times a day. It can be sedating, however, which is a concern for children who are in an educational setting. Adults occasionally say they cannot drive or concentrate on their work when they take baclofen. It is often used for individuals with CP who have significant spasticity, combined with cognitive impairment, in order to improve ease of care. People who take baclofen should have their liver functions checked with a blood test every one or two years, as baclofen can cause liver inflammation. Baclofen is known to trigger seizures in patients with epilepsy, so it is often not given when seizures are a concern.

-Tizanidine (Zanaflex) is taken once or twice a day, occasionally three times a day. It can be more sedating than baclofen, so it is best to try a nighttime dose so that the sedation leads to sleep and helps with spasticity for the morning care routine. It can lower blood pressure, so it should be carefully monitored if the patient is on other medications for blood pressure.

-Diazepam (Valium) is commonly used to decrease tone after surgery. It is also used on a regular daily basis. It is also very sedating, so much so that it is not used commonly in adults who need to drive or work. It can be given up to four times a day.

-Trihexphenidyl (Artane) is particularly useful for dystonic twisting motions. It is taken 2-3 times a day, and has the same problems with sedation. It can also trigger seizures, and cause agitation.

There are a few other drugs used, such as gabapentin, dantrolene and clonidine. CBD oil has become popular, with many people saying it is helpful, but this has not been formally tested. As noted, all of these medications have side effects including sedation, so physicians tend to stay away from them in children where interference with education is a concern. Many adults are placed on baclofen, and then the doctor assesses if the benefit outweighs any side effects. Often, people will try different medications to see what works best, with the least side effects for them.

While the medications taken by mouth noted above treat hypertonia in the whole body, injected medications are used to reduce high tone in a specific muscle. The most common medication used for this is botulinum toxin A, which is marketed as Botox, Xeomin or Dysport. Botulinum toxin targets specific problems such as walking up on toes, tight hamstrings leading to crouching, difficulty in separating the legs, or difficulty with reach. The medication is injected into the specific muscle interfering with the desired action, often using ultrasound or electrical stimulation to guide the injection. However, many clinicians do the injections simply based on their knowledge of anatomy without a guidance tool.

The procedure is often done under anesthesia or sedation, especially when there are multiple injections or very deep muscles are being treated. When the injections are done in a clinic without sedation, there are ways to numb the skin and distract the patient (especially a child) to make the procedure easier. Botulinum toxin injections are effective in reducing tone for three to six months, sometimes up to a year. At a certain point, the patient notices that the effects of the medication have worn off and the muscle has stiffened again. At that point, the procedure can be repeated. Many patients come to the physician's office at regular intervals to have repeat injections.

> **PEOPLE WITH SPASTICITY WILL HAVE A CONSTANT TIGHTNESS OF THEIR MUSCLES, WHICH INTERFERES WITH THE ABILITY TO CONTROL THE BODY AND COORDINATE MOVEMENTS.**

The benefits of botulinum toxin injections depend on where they are placed, and include improved reach, grasp and opening of the hand; improved walking patterns due to looser muscles in the legs, especially the hamstrings and gastric-soleus groups; and ease of care, including toileting and dressing. These injections have other uses as well, including injections in the mouth to decrease drooling, or in the neck to help tight muscles there.

Botulinum toxin injections can, in rare cases, cause allergic reactions, bleeding and pain at the injection site, and infection. There is occasionally some spread to muscles that were not targeted that can have unpleasant effects. The injections can also lose effect due to the body creating antibodies against the medicine. When this happens, switching to a different form such as botulinum toxin B may be helpful. It is also important to note that insurance approval is required before doing the injection, leading to a wait and another appointment. Sometimes, when patients live far from their treating physician, it can be useful to meet virtually to discuss the injections, so that the physician can seek approval and then have the patient come in for the injection.

Phenol and alcohol injections are less common but still used at times, especially when the amount of botulinum toxin that can be used is limited by body weight. These injections are injected in similar areas and have similar benefits to botulinum toxin injections. Phenol destroys nerves, rather than block them as botulinum toxin does, and can have more complications such as post-injection pain. However, complications are rare, and they can be longer lasting. They always require ultrasound or electrical stimulation to locate the point of injections, so they are generally done with sedation or anesthesia.

> **THERE ARE MANY DIFFERENT WAYS TO TREAT HYPERTONIA. THE CORRECT CHOICE WILL DEPEND ON THE GOALS OF THE PATIENT, THE FAMILY AND THE TREATING PHYSICIAN, AS WELL AS THE FAMILY'S PERSONAL BELIEFS ABOUT MEDICATIONS AND SURGERY**

Surgical treatment for hypertonia includes orthopedic surgery, such as muscle lengthening procedures. In these operations, the surgeon will release some muscle fibers, split the muscle and sew the two halves together as a longer muscle, or use other techniques to make the muscle longer. In CP, muscles do not grow normally and are often too short for the bones they cover, leading to decreased range of motion and movement. The procedure tends to weaken the muscle, but generally improves walking and movement. Children will wear a cast for several weeks, sometimes followed by a splint, and then benefit from physical therapy to regain strength and learn new patterns of movement. Common orthopedic surgeries in CP include lengthening the gastric-soleus (the muscle attached to your heel cord), the hamstrings, and the muscles that flex the hips. After surgery, the patient has more movement of their muscles and can walk in a more normal pattern. These surgeries also address contractures, which interfere with function, dressing and other care.

The selective dorsal rhizotomy has become a common neurosurgical procedure to treat hypertonia. In this procedure, the surgeon opens up the skin, muscle and bone over the spinal nerves. They then use electrical stimulation to figure out which nerves are most involved in the spastic tone, and they cut those nerves. After surgery the patient requires intensive therapy, usually initially as an inpatient in the hospital, to learn how to use their body with decreased tone. Rhizotomy has been done most often to improve walking and movement, and children who have undergone rhizotomy can learn better control of their movements and gain gross motor skills. The benefits will be seen mostly in the legs, and much less so in the arms, because the procedure focuses on the nerves to the legs. Over the past few years, it has been used for individuals with more general spasticity in a procedure called a "palliative rhizotomy,' designed just to decrease tone throughout the body and ease care. Studies have shown that the rhizotomy decreases tone, increases function, and has good long-term results with minimal complications.

The intrathecal baclofen pump involves the placement of a pump in the body with a catheter going to the back. It pumps small amounts of the baclofen into the spine, which is more effective than taking the medication by mouth and does not have the side effects of sedation and seizures. The pump reduces tone throughout the entire body, which allows more freedom of movement. It is a life-long commitment in that it needs to be filled by a painless injection every few months. There are rare mechanical and other types of problems with the pump, but some can be life threatening, so having a good management team is important. People who have the pump report freer movement, improved ability to transfer and greater ease of care.

In summary, there are many different ways to treat hypertonia. The correct choice will depend on the goals of the patient, the family and the treating physician, as well as the family's personal beliefs about medications and surgery, and their ability to comply with the aftercare protocol. An open discussion of these issues is important when choosing the correct treatment for hypertonia. ●

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Reconsidering Botox: Points to Ponder

New evidence suggests that less may indeed be more.

Sushi Zucker, MsPT
Shaindy Silber, PT, DPT
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Julie H Perfect, PT, DPT, PCS

Dear Parents,

As physical therapists, we spend a lot of our professional time in the clinic providing direct care during our sessions, but behind the scenes our professional time is also spent on investigating current research and evidence based practice. This is how we maintain our commitment to providing the best possible care for your child. Learning, for anyone in the healthcare field, extends far beyond our classroom years. As scientific knowledge grows and evolves we must respond by seeking out the current evidence in our fields. In that vein, we want to share some important information regarding the use of Botox in the long-term management of cerebral palsy.

Over the past three decades much research has been published supporting the use of Botox (short for Botulinum Toxin or BoNT-A) to assist with management of spasticity and to improve passive range of motion in children with cerebral palsy (CP), and it has been adopted as a standard of care. Use of Botox has been celebrated by the medical community as it has effectively been able to reduce the number of surgeries that children diagnosed with CP undergo during their growing years, [1] which is a very important advancement in clinical care. However, there is mounting evidence that challenges Botox's efficacy as a long-term solution for functional motor improvement in this population. There is a growing understanding in both the medical and physical therapy community that Botox as a first choice intervention, needs more review. In fact, Dr. Kerr Graham, who was one of the earliest and strongest proponents of Botox injections as a treatment for spasticity, has recently publicly recanted his position at multidisciplinary scientific conferences. Dr. Graham and others have noted that use of Botox results in some undesired effects in the muscle itself, causing long term weakness and possibly impacting the density of the bone.[2] He currently recommends Botox be limited to only a few injections over a lifetime and has stated that more research is necessary into the risks and rewards of Botox use. Let us look deeper into the pros and cons of Botox and examine the more pressing question: how does Botox impact function?

To fully understand the debate we must know how our bodies typically generate movement and how Botox impacts muscles. When an individual wants to move, the brain sends out a signal which is transmitted through a series of nerves to the muscle itself, activating it and causing the limb to move. Through continued use, we gain strength and develop adequate balance to hold our bodies up and to move and function against the force of gravity. Botox is actually the Botulinum Toxin, which is produced by the bacteria Clostridium Botulinum. When ingested it causes a life-threatening type of food poisoning called botulism. The individual suffering from botulism poisoning loses the ability to activate their muscles, cannot function, and essentially becomes paralyzed. Although the bacteria and toxin it produces are very dangerous when ingested, it is important to note that it has been approved for cosmetic injections and to manage spasticity as safe practice.[3]

Why and how is Botox used to treat CP? Cerebral palsy is a disorder of movement and posture. Initiating and controlling muscle activation and balancing for functional movement against gravity can be affected. Muscle weakness is a primary impairment (a significant issue). Muscle tone (which is the amount of tension in a relaxed muscle), can also be affected. Muscle tone is not the same thing as muscle strength. Normal muscle has an amount of tension all the time, which helps our bodies maintain our chosen positions against gravity and it provides a state of readiness so that our muscles can be activated for purposeful movement. Many individuals with CP have too much muscle tone or stiffness in their muscles, making it harder to move. Even though it often seems like a muscle with spasticity is too strong, the muscle is really still very weak. The stiffness of the muscle simply makes it feel strong.

Over the past three decades much research has been published supporting the use of Botox to assist with management of spasticity and to improve passive range of motion in children with cerebral palsy.

Children with CP are not typically born with passive limitations of joint movement or bony deformities.[4] Restrictions in passive movement develop over time from a lack of variety of movement opportunities. In 2003, Graham and Selber noted that spasticity is not the most important factor determining prognosis in cerebral palsy. Muscle weakness and an inability to activate appropriate muscles for functional are more important.[4]

When used to treat spasticity or improve range of motion, small doses of the botulism toxin are injected into the desired muscle which then blocks the signal from the nerves that make the muscle move.[5] A protein from the toxin binds and is absorbed into the nerve ending where it meets the muscle. It impacts the internal working of the cell and prevents the transmission of the signal from the nerve to the muscle, effectively blocking a muscle contraction. This is called chemical denervation and results in paralysis of the treated muscle fibers. As the muscle now cannot receive signals from the brain, tone and strength cannot be generated. Since muscle tone is decreased, passive range of motion may increase. The muscle will begin to atrophy (which is the medical term for muscle shrinkage or wasting due to disuse).[6] You may notice the results from your child's Botox injections within a few days, but it can take more than two weeks for the full effect to be seen.

How long will a Botox injection impact a muscle? Eventually, new nerve terminals are grown, and transmission of nerve signals resumes. However, during the time period when the muscle was weakened, changes are happening within the muscle itself. Those changes and whether or not the changes revert as new nerve terminals are grown is what determines muscle recovery.

To help understand, we look at animal studies. Although we know animals are less responsive to Botox than humans, we can extrapolate what we know about how rat muscle growth relates to human muscle.[7] These studies reveal that the injected muscles have an 88-95% reduction in strength and that contractile tissue was replaced primarily with fat.[8] The studies reveal that the peak loss of muscle size in children may occur 16 months following injection and that it may be necessary to wait over 17 years for a human muscle to recover before repeating the injection! Similarly, the marked reduction in muscle fiber size seen following a second injection could persist in adult humans over a year following injection. Studies in human volunteers continue to show muscle atrophy after an injection of Botox for at least 12 months.[6] No further testing was performed to determine true recovery. The study concludes that repeated injections of Botox may have a cumulative adverse effect on muscle growth in children with CP and needs to be addressed.[8] Two studies on healthy human volunteers did reevaluate the muscles after they had been determined to be "clinically recovered" and found the muscle had actually not recovered and that atrophy was actually still present and continued to persist at the 12-month mark![6] No study has yet been done to determine the time of true muscle recovery.

A closer look at what is happening to the muscle at the cell level is very revealing. Imaging studies show that muscle fibers (the part of the muscle that is responsible for creating a contraction) are partially lost and replaced with fat and connective tissue, undergoing fibrosis (becoming stiff) and necrosis (cell death), making the muscle ineffective. Fatty and connective tissue does not have any ability to contract or generate motion, resulting in a permanent decrease in the ability of the muscle to generate strength. Furthermore, studies have found that in addition to these changes occurring in the injected muscles, these same changes are noted post injection in muscles both neighboring the injection site as well as on the other limb with poor force production recovery.[8] A decrease in bone density in neighboring bone segments is additionally observed.[2] This is concerning because impairments of muscle and bone health are already a major clinical problem in children with cerebral palsy at baseline,[9, 10] which is now being compounded by the application of Botox.[2]

The literature is clear that Botox injections create passive range of motion by decreasing the muscle activation that presents as ‘increased muscle tone’, but it does not consistently state that it leads to long term improved function.

Repeated injections can lead to long-term weakness and compromise the overall motor function in individuals with cerebral palsy. In recent studies, it has been shown that a muscle that received Botox never regains its full functional strength.[6] It is not currently known if these changes at the molecular level are reversible. The answer to the question of how long the effects of a Botox injection will last is that we actually don't really know.

This tells us that there is a need to revise clinical protocols by using Botox more thoughtfully, less frequently, and with greatly enhanced monitoring of the effects on injected muscle for both short-term and long-term benefits and harms.

Ok, so now that we've all participated in a science lecture, what does all this mean for us practically?? To review: the literature is clear that Botox injections create passive range of motion by decreasing the muscle activation that presents as ‘increased muscle tone’, but it does not consistently state that it leads to long term improved function.

So does Botox improve function? It is well documented that Botox injections will result in short-term improved range of motion and decreased muscle activity, which is often reported as decreased spasticity. Even though the range of motion may be increased, studies actually show that Botox was not effective in preventing or reducing joint deformity and suggests that it may instead promote deformity.[12]

Wait! How would deformity be promoted if range is improved? The studies explain that the observed muscular changes are not actually a change in spasticity or muscle tone, but instead a product of impairing the muscle, creating weakness. This makes it harder for an individual with cerebral palsy to generate functional movement, not easier, which ultimately leads to the development of muscle deformities rather than a reduction in muscle deformity.

Some studies do indeed demonstrate improvement in gait in some subjects; however, the changes are inconsistent, small in magnitude, and short-lived.[14] Changes in functional activities and participation levels have rarely been reported in studies to date. Why is this so? If studies find improved range and decreased muscle activity, why is there no significant change in function? The answer to this lies with the changes happening to the muscle. Let's put the pieces together.

When a muscle receives a Botox injection, the neuromuscular junction does not function, and contractile fibers are replaced by fat, which cannot be recruited to perform tasks and thereby impairs the muscle. Post Botox, children therefore cannot appropriately recruit muscles to perform activities, strengthen, or experience motor learning. These findings clearly explain why having more range of motion is not translating into improved function and actually prevents proper strengthening and skill development from occurring. After all, what use is movement in joint range of motion if the muscle cannot be activated?

Although the child with CP misfires muscles, triggering them too soon, or too strong, or in nonfunctional combinations of muscles working together, those muscles are still very much necessary for function.[5] Spasticity is a measure of tension in a muscle that is resting, not a measure of how strong the muscle is. Spastic muscles are not overly strong, they are weak.

Let's take the adductors, for example, which is a large muscle on the inner thigh that brings the legs together. The adductors are often targeted for Botox injections due to scissoring (crossing of the legs). When typical walking is analyzed, the adductors are noted to be active throughout the gait cycle and are imperative to normal functional walking. Removing the adductors impacts gait and impairs function. A child with CP needs to learn how and when to recruit the adductors during gait. By injecting them with Botox, they are no longer available to be called upon to function and the child cannot learn to activate them as needed.

We can clearly see that although there may be short term reduced spasticity as well as increased range of motion, if the long term result is decreased functional strength then the use of Botox may not help in reaching that goal. Overall, the short-term benefits of Botox injections may not align with the intended goals of long-term functional improvement. Given these considerations, it may be best to explore other approaches that have demonstrated long-term benefits in muscle strengthening and functional improvement like neuromuscular electrical stimulation[15, 16, 17] and whole body vibration[16, 18] to name two.

> Overall, the short-term benefits of Botox injections may not align with the intended goals of long-term functional improvement.

It is important to note, however, that there may be times when Botox is necessary due to hygiene, inability to dress or transfer, especially if other treatment options are not an option for the family or have not been effective. There are situations when Botox can be a positive treatment, such as if a child is lacking so much range or has such profound spasticity that their basic care needs cannot be met, and independent movement or increased functional mobility is not the anticipated end goal.

It took decades for the standard of care in cerebral palsy to transition from multiple (often yearly!) surgeries to administration of botox injections. Considering the new evidence that has been coming to light, it might be time for the standard of care to shift once again. Unfortunately, in healthcare it can take 15 years for evidence to translate to practice,[4] however you don't have to wait 15 years to ask questions and have conversations to find out if there are other, and potentially better, options for your child.

We understand that each child's condition and functional presentation, as well as long-term goals, are unique, and decisions about their care should be made in consultation with a healthcare team. This information is meant to empower you with knowledge and tools and even to have information to 'stow away' to broach with your team of providers and caregivers at the right time that is right for you. ●

References:

1 Gormley M, Chambers HG, Kim H, Leon J, Dimitrova R, Brin MF. Treatment of pediatric spasticity, including children with cerebral palsy, with Botox (onabotulinumtoxinA): Development, insights, and impact Medicine 2022;102:S1(e32363).

2. Tang MJ, Graham HK, Davidson KE. Botulinum Toxin A and Osteosarcopenia in Experimental Animals: A Scoping Review. Toxins (Basel) Mar 14 2021; 13(3)doi: 10.3390/toxins 13030213

3. Satriyasa, B. K. Botulinum toxin (Botox) A for reducing the appearance of facial wrinkles: a literature review of clinical use and pharmacological aspect Clin Cosmet Investig Dermatol. 2019; 12: 223–228.

4. Melnyk, B.M.The Current Research to Evidence-Based Practice Time Gap Is Now 15 Instead of 17 Years: Urgent Action Is Needed. (2021). Worldviews on Evidence-Based Nursing, 18, 6; 318. doi:10.1111/wvn.12546

5. Picelli A, Filippetti M, Sandrini G, et al. Electrical Stimulation of Injected Muscles to Boost Botulinum Toxin Effect on Spasticity: Rationale, Systematic Review and State of the Art. Toxins (Basel). Apr 23 2021;13(5)doi:10.3390/toxins13050303

6. Fortuna R, Vaz MA, Youssef AR, Longino D, Herzog W. Changes in contractile properties of muscles receiving repeat injections of botulinum toxin (Botox). J Biomech. Jan 04 2011;44(1):39-44. doi:10.1016/j.jbiomech.2010.08.020

7. Minamoto VB, Suzuki KP, Bremner SN, Lieber RL, Ward SR. Dramatic changes in muscle contractile and structural properties after 2 botulinum toxin injections. Muscle Nerve. Oct 2015;52(4):649-57. doi:10.1002/mus.24576

8. Fortuna R, Horisberger M, Vaz MA, Herzog W. Do skeletal muscle properties recover following repeat onabotulinum toxin A injections? J Biomech. Sep 27 2013;46(14):2426-33. doi:10.1016/j.jbiomech.2013.07.028

9. Shortland A. Muscle deficits in cerebral palsy and early loss of mobility: can we learn something from our elders? Dev Med Child Neurol. Oct 2009;51 Suppl 4:59-63. doi:10.1111/j.1469-8749.2009.03434.x

10. Modlesky C.M., Zhang C. Complicated Muscle-Bone Interactions in Children with Cerebral Palsy. Curr. Osteoporos. Rep. 2020;18:47–56. doi: 10.1007/s11914-020-00561-y.

11. Koerte IK, Schroeder AS, Fietzek UM, et al. Muscle atrophy beyond the clinical effect after a single dose of OnabotulinumtoxinA injected in the procerus muscle: a study with magnetic resonance imaging. Dermatol Surg. May 2013;39(5):761-5. doi:10.1111/dsu.12125

12. Gough M. Does botulinum toxin prevent or promote deformity in children with cerebral palsy? Dev Med Child Neurol. Feb 2009;51(2):89-90. doi:10.1111/j.1469-8749.2008.03247.x

13. Nigam PK, Nigam A. Botulinum toxin. Indian J Dermatol. 2010;55(1):8-14. doi:10.4103/0019-5154.60343

14. Multani I, Manji J, Hastings-Ison T, Khot A, Graham K. Botulinum Toxin in the Management of Children with Cerebral Palsy. Paediatr Drugs. Aug 2019;21(4):261-281. doi:10.1007/s40272-019-00344-8

15. Liron-Keshet, Shiri, et al. "The Effect of Therapeutic Electrical Stimulation in Children with Diplegic Cerebral Palsy as Measured by Gait Analysis." Basic Appl Myol, vol. 11, no. 3, 2001, pp. 127–132, media.kenanaonline.com/files/0017/17177/paper_16.pdf. Accessed 8 Jan. 2024.

16. Naro, Antonino, et al. "Breakthroughs in the Spasticity Management: Are Non-Pharmacological Treatments the Future?" Journal of Clinical Neuroscience, vol. 39, May 2017, pp. 16–27, https://doi.org/10.1016/j.jocn.2017.02.044.

17. Bosques, Glendaliz, et al. "Does Therapeutic Electrical Stimulation Improve Function in Children with Disabilities? A Comprehensive Literature Review." Journal of Pediatric Rehabilitation Medicine, vol. 9, no. 2, 31 May 2016, pp. 83–99, https://doi.org/10.3233/prm-160375.

18. Cheng, Hsin-Yi Kathy, et al. "Effects of Whole Body Vibration on Spasticity and Lower Extremity Function in Children with Cerebral Palsy." Human Movement Science, vol. 39, Feb. 2015, pp. 65–72, www.sciencedirect.com/science/article/pii/S0167945714001900, https://doi.org/10.1016/j.humov.2014.11.003. Accessed 15 May 2019.

Cognitive Rigidity

Dr. Dovid Berkowitz, Psy. D

I sat down with Dr. Berkowitz and had a fascinating and insightful discussion with him on the topic of rigidity in children with cerebral palsy (CP). His thoughts really opened my mind to ideas and supports that could be applied not only to children with CP but to those with other disabilities, as well as neurotypical children. The questions below were generated by our readers. Let's see how Dr. Berkowitz fielded those questions.

1. What contributes to the manifestation of rigidity in individuals with CP? What cognitive processes underlie this behavior, and what is the understanding of it?

The root of rigidity often occurs when children, often together with the adults in their lives, establish their behavior patterns (both productive and non-productive). A structured schedule is beneficial because it provides predictability and maintains balance in their day. However, challenges often arise when change occurs to their strict schedule, which often distresses the child, particularly children who become overly reliant on and rigid within their daily routine.

This is why it is so crucial to teach flexibility to your child. This is a skill that needs to be taught, and the best way to do so is by demonstrating its application in your own life. While a consistent schedule is valuable, it is equally important to teach your children how to adapt to the changes. An example of a way to encourage this new behavior of flexibility can be:

Try making small modifications in routine, such as altering the color of a marker that is generally used or reading a different book before bedtime. By slowly exposing children to these small changes, they will be able to adapt more easily to any changes in their daily routine. This exposure for children helps them understand that flexibility is a skill they will learn, and that it will benefit them.

2. What is an advisable mindset for parents when confronted with their child's inflexibility? How should one manage their own agitation while witnessing their child's rigid behavior?

It is essential to demonstrate flexibility as a parent. You will then proactively instill the concept of flexibility in your child by incorporating it into your own daily life situations. Notify your child when there are instances in your own life where you exhibited flexibility and explain how it positively influenced the outcome. You can do this in an overdramatized manner to add effect. For example, a parent might say, "oh my, I can't believe we are out of butter! I really like butter on my toast (dramatic pause). Oh well, I guess I will use margarine... but that's okay!"

By modeling flexibility, parents not only provide a practical example for their children, but also create a learning environment for the child in the home. This will equip the child with the tools that they need to navigate the real-life scenarios that require flexibility, while creating a more resilient and adaptable mindset.

While a consistent schedule is valuable, it is equally important to teach your children how to adapt to the changes.

3. How can I effectively facilitate a transition or manage change when my child is exhibiting rigidity and struggling with the adjustment?

Ways to effectively facilitate transition and change when dealing with tough behaviors can involve using words that recognize the struggle, emphasize flexibility, and ask the child to suggest a solution or pick from some choices. For example, you might say, "wow, I realize we don't have your regular salad dressing today... that must be tough. I guess we will need to be flexible today, I had to be flexible this morning when we were out of butter. Can you think of a way to be flexible without your salad dressing? Hmmm, that's a tough one. Here are some choices: you can use Mommy's pink dressing or you can eat your salad without dressing. Why don't you decide?" Rather than forcing the struggle, you will contribute to fostering adaptability in the child.

4. In what ways does the rigidity observed in a child with a neurological disorder differ from that seen in a typically developing child? Additionally, what aspects should not be misconstrued when examining rigidity in these contexts?

While the rigidity may be more pronounced in children with neurological disorders, neurotypical children also exhibit similar behaviors. It is important to recognize that these behaviors are learned behaviors. A behavior that a person is demonstrating is being maintained by something or someone in their environment due to reinforcement. If a behavior repeats itself, something is keeping it going. This is a much bigger topic in and of itself and it can be addressed at another time.

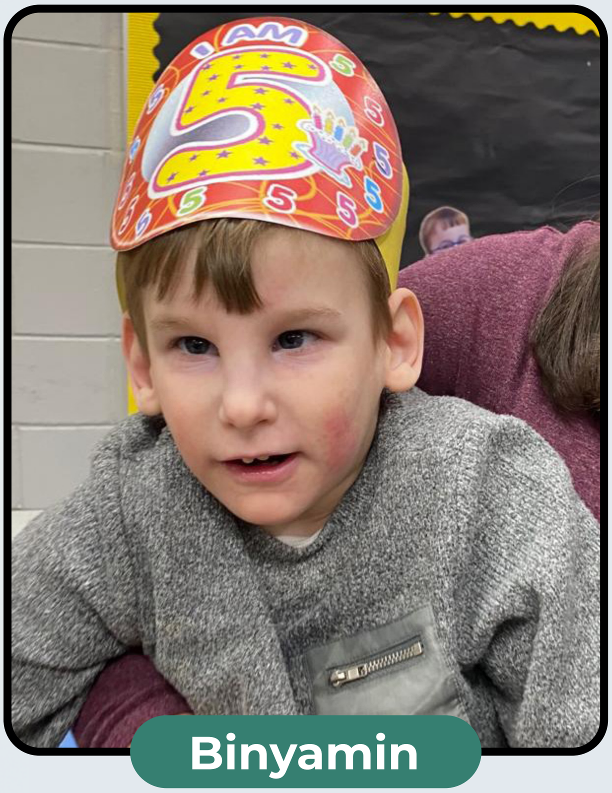
5. What is the reason for the necessity of different guidelines in addressing rigidity in children with neurological disorders compared to neurotypical children?

In regards to requiring entirely separate guidelines for these children, it should be noted that the fundamental principles and guidelines remain the same. However, when it comes to children with neurological disorders, the guidelines may need an increased amount of repetition and consistency, particularly with a focus on positive reinforcement. This may be due to the child's processing timing for acquiring new behaviors. Therefore, more time may need to be spent on the issue, more focus on a reward system may need to take place, and a slower pace of instruction may be necessary for treating rigidity in children with neurological disorders. ●

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

Ahuva

Ava



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CHIZUK BOOST

Rabbi Shia Hershkowitz

It is the will of the Ribono Shel Olam that the world functions in a seemingly natural fashion. Hashem guides and supervises us through the channels of nature in a way that no act and sequence should be changed by miracles.

There is a halachic discussion about whether one may daven for something that seems impossible to change, e.g., to daven on behalf of an individual who has reached a 'natural dead end': when doctors give up hope or when someone is born with a physical or mental disability. We may want to ask Hashem for something beyond natural means, to daven for a miracle, something beyond 'nature.'

The gemara (Berachos 60a) says, "Somebody who prays for something in the past, such as somebody who enters a city and hears a cry of anguish, upon which he prays that the cry should not be from his own home, or somebody whose wife is pregnant and is after forty days of conception and prays that his child should be a male – this is a prayer in vain (tefilas shav)." At this point in the pregnancy, the child's gender is already fixed; we do not daven for such a change. The Shulchan Aruch (Orach Chaim 230) rules accordingly that one must refrain from such prayers and concludes that a person should "pray for the future and give thanks for the past."

The Rema (Orach Chaim 187:4, 682:1) writes that if a person forgets to say al hanissim during birkas hamazon, he should add a special harachaman addition at the end of bentching, which asks Hashem to "perform miracles for us as He did in those days." (Following this, he should recite the full al hanissim and bimei...) As mentioned before, how can this prayer for miracles be justified, given that it is generally wrong to pray for miracles? The poskim give a few answers to this question.

The Bechor Shor distinguishes between an individual who should refrain from praying for miracles and the general community, for whom it is correct to ask for miracles. The Yeshuos Yaakov (682:2) distinguishes between a neis nistar, a hidden miracle, and a neis nigleh, an open and revealed miracle. Benefiting from a personal or hidden miracle will diminish a person's merits; therefore, he should not pray for such a miracle. However, a public miracle will not diminish a person's merits, since, on the contrary, the kiddush Hashem generated by a public miracle augments a person's merits. It is, therefore, permitted to daven for a public miracle involving kiddush Hashem. There are other differences mentioned in the poskim as well.

The prohibition of tefilas shav is likely said only in such a way that there is no imaginable natural possibility that the solution can only be brought about by a miracle. Under the influence of nature, such a result is entirely impossible, such as praying for the dead to live again or for a change of the gender of a fetus. However, tefillah for something that can be achieved naturally, even if, according to current medical knowledge, it seems impossible and is not ‘natural,’ may be permitted. Things can change with new medical research, and it follows the course of nature. One may daven for such a matter, even though this ‘natural phenomenon’ is not yet known to us. It is not considered a futile prayer, and therefore, it is permissible.

For example, one may daven for a woman who does not have a uterus to have a baby, because recently, the doctors determined that a uterine transplant can be performed successfully, same as with other organs. It is permissible to pray for someone who, according to doctors, is ‘brain dead.’ Because there is a possibility that, hopefully, soon, Hashem will grant doctors the knowledge to heal the brain, even if it is not yet a medical option. It is certainly permissible to pray for a child born with developmental or neurological disabilities to be healed. Before doctors found antibiotics, everyone davened for someone with an infection to recover. So, too, one can and ought to daven that the disabled child is happy and reaches its utmost potential, and that doctors uncover the right medicines and procedures to relieve these disorders.

> A person must believe that Hashem listens to everyone’s tefillos and that He can heal and change any situation, no matter what. Hashem can create new medical interventions and even do so naturally.

The gemara (Berachos 10a) says that the navi Yeshaya visited King Chizkiyahu on his deathbed. Yeshaya told Chizkiyahu that because he had never had children (to avoid the evil offspring that he knew he was destined to have), he would die very soon and forfeit his olam haba. Chizkiyahu asked Yeshaya to allow him to marry his daughter, and, hopefully, their combined merits would nullify the gezeira against him. Yeshaya replied that it was useless because the decree had already been determined. Chizkiyahu responded to Yeshaya — “I have a tradition passed down from the house of my father’s father that ‘Even if a sharp sword is resting on your neck, don’t hold yourself back from rachamim.’ “ Right then, Chizkiyahu turned his face towards the wall and davened. What was the “wall?” Rebbe Shimon ben Lakish says it refers to the walls of his heart. Chazal tell us that Chizkiyahu’s tefillos were answered, and he lived for many years afterward.

The gemara states (Rosh Hashana 18a:) Rabbi Meir used to say that for two people who suffered from the same illness or two criminals convicted of the same crime, there is a possibility for one to recover and the other one not to recover; one to be acquitted and one to be charged. One will live, and one will die. Why is this so? One prayed, and his prayers were answered; the other prayed, and his prayers were not answered. The gemara elaborates that the one who prayed a “complete prayer” was answered, and the one who did not pray a “complete prayer” was not answered.

What is the definition of a “complete prayer” versus an “incomplete prayer”? It is unlikely that the difference is one of kavannah (intent). It is doubtful that a person’s mind would wander when he is close to death. The gemara does not mean that one of them “spaced out” while praying and the other did not.

Rav Elya Lopian explains that a “complete prayer” (tefillah sheleimah) indicates that the person believes in the power of his prayer. He believed in Hashem’s powers and the power of his prayers, and therefore he was answered. One person had confidence in the power of tefillah, and the other person did not have confidence that his tefillah would be answered. A person must believe that Hashem listens to everyone’s tefillos and that He can heal and change any situation, no matter what. Hashem can create new medical interventions and even do so naturally.

The Kotzker Rebbe’s sister was once very sick and doctors could not find a cure. She went to her brother, the Rebbe, and asked that he daven for her. He looked at her and said, “There is nothing I can do for you,” and slammed the door in her face. His sister started crying, “Master of the Universe, my brother won’t help me. You must help me!” The Kotzker Rebbe opened the door and said, “This is what I wanted to hear. It is not the Kotzker Rebbe who can help you or the doctors who can help you; it is only the Almighty who can help you. I just wanted to bring you to that realization. Once you have come to that realization, you will be fine.” That is the definition of a “complete prayer.”

Let us continue to daven to Hashem that very, very soon, we will be zoche to the geula sheleimah and a complete recovery for everyone. ●

Helping Special-Needs Children: The True Ratzon Hashem

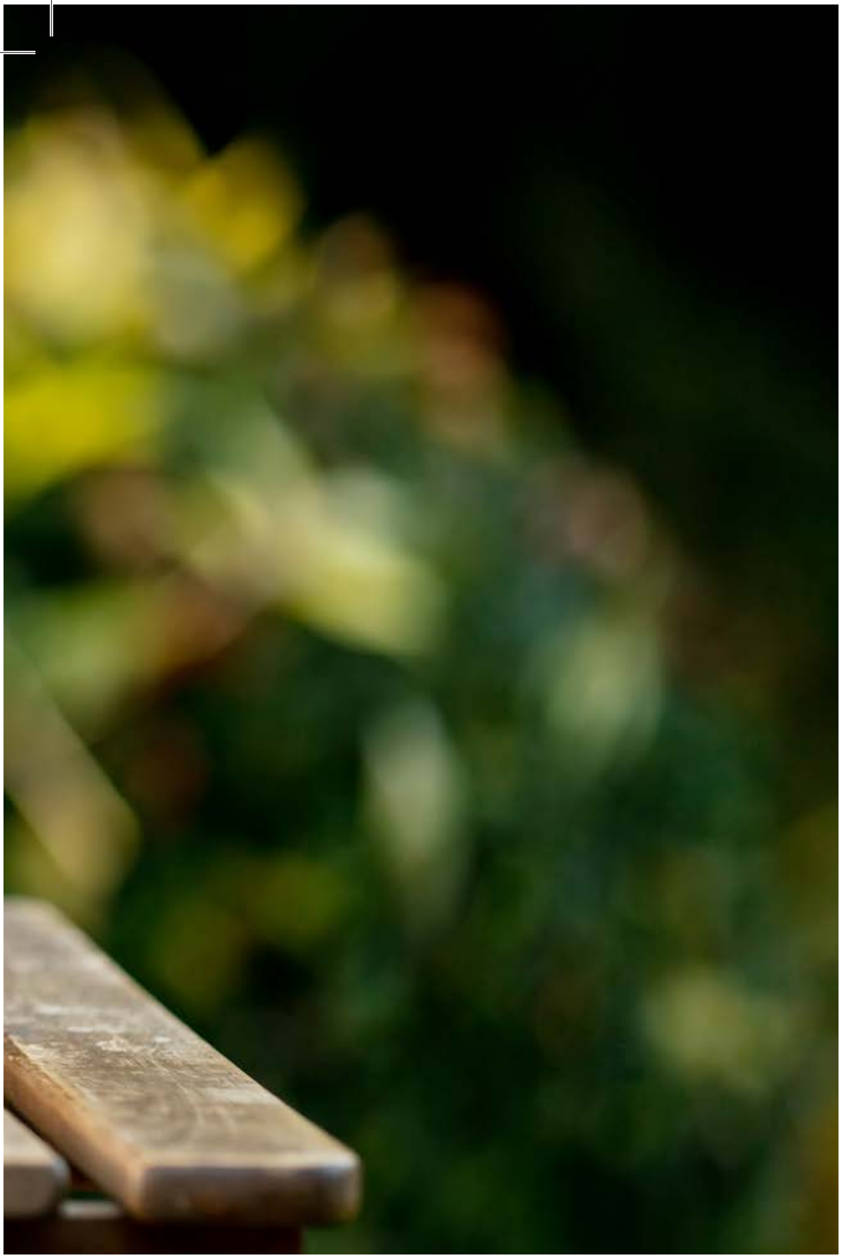
Rabbi Leibish Langer

There is a story told about Reb Mendel Pshitik, a well-known Chassid that showed his love for mitzvos. After WWII, the Klausenberger Rebbe had four pairs of tzitzis to distribute. Many stood in line to be the ones to get the zechus of using the tzitzis. The Rebbe decided that he would make a goral to determine who would be chosen. At that moment, Reb Mendel declared that he must be the one to get to use the tzitzis. He ripped his jacket in the middle, and he declared that he had four corners and that he needed to put on the tzitzis. The Rebbe said, "With such desperation for the mitzvah, I'm sure you will be rewarded by Hashem to get a pair." Sure enough, the goral was done, and Mendel Pshitik won a pair! When you are sincere about doing a mitzvah, there is an outpouring of siyata dishmaya.

A story was once related by the Avnei Nezer zatzal, about a Ba'al Menagen who was honored to sing in front of the Rebbe. The Rebbe asked him to stop singing. The Rebbe understood that the Ba'al Menagen had not learned any gemara the entire week! The singer told the Rebbe privately, "I'm a businessman and I'm used to learning gemara in depth. I can't learn gemara quickly and I have limited time." The Rebbe replied, "If you learn gemara everyday with Rashi you will be a simple talmid chacham. But if you don't learn because you want to learn only b'iyun, you will be a gaon, a brilliant am h'Aretz."

Just as the Ba'al Menagen wanted to learn only in a grand, deeper way, so too there are people who want to contribute to helping special needs children only in a very grand way, and so they don't have sufficient time for this endeavor. Like the Ba'al Menagen who did not learn because he only wanted to learn b'iyun, those people get nowhere in helping special needs children, because they only want to help in a grand way. On the other hand, those people who start with small projects end up accomplishing tremendously.

One example of this is the story of how Hamaspik began. I generally go once a year to a Hamaspik Shabbos in Woodridge to entertain the special needs children.



I was told the story of how this program began; a number of years ago, a young girl, along with a few friends, babysat some special needs children, to relieve the parents so they could have some menucha on Shabbos. She took the kids to her house, and it was a life saver for the parents. Eventually, word got out and more special needs children joined the babysitting group, so the parents could have some much needed relief. It became an overwhelming project for a single girl to handle, and so Hamaspik helped continue and form this outstanding project. It grew into what's now known as Ahavas Golda. Another girl joined to help this project boom. It has become a wonderful place for special needs children to rejoice and enhance their lives, while their parents enjoy well deserved respite services.

A common refrain that is often heard is, "Time! Time! I'm so busy and I don't have time for chessed." This is what impedes people from accomplishing chessed projects. Let us explore how our gedolim respond to this thought.

The story is told about the Rav of Lodz, Rav Eliyahu Chaim Meisel zatzal, who was a giant in Torah. He was always involved in doing chessed. He would borrow money to help the poor and would help downtrodden people in many different ways. Once, a group of rabbanim got together; Rav Chaim Brisker, zatzal, was the chairman. One Rav criticized Rav Meisel, saying that he was too involved in chessed, and it affected his learning schedule.

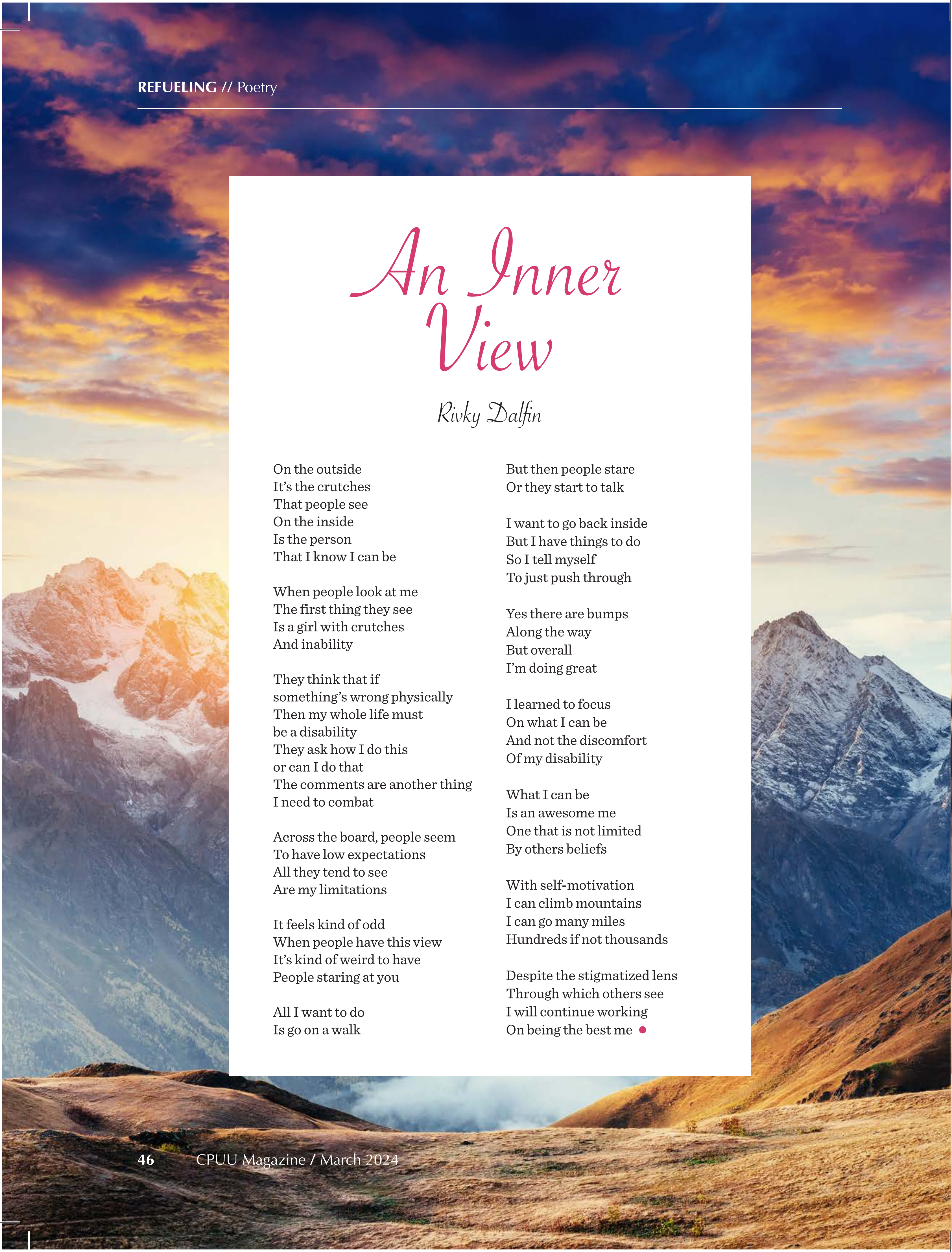
Rav Chaim responded, "If a Rav closes his gemara to do chessed, then even when his gemara is closed it's really open, and if a Rav doesn't close his gemara to do acts of chessed, then even when his gemara is open it is considered closed!!!"

When these opportunities knock on our door we should respond with eagerness. Special needs children and their issues shouldn't be viewed as a private family's challenge. These children belong to Klal Yisrael. We know that they are great neshamos, and we are all responsible to help these holy neshamos fulfill their purpose. The parents are taxed with the burden. One day the parents will cherish the great zechus they were given to raise these children. We do not question why. We live by the dictum of emunah, with the heroic answer of Hineini. What do You want me to do? I am ready. The parents answer to the call of Hineini every hour and moment. They invest all their strength in raising these children.

The Menoras Hamaor states it is a segulah to keep the used hoshanos after Hoshana Rabbah. They act as protection from aveiros and tzaros. The gematria of aravah is 277, as is zera and Anah Hashem Hatzlicha Na. We consider these children to be the living zera. Certainly all the chessed that is invested in these precious neshamos will bring tremendous hatzlacha to you and your entire family and all those who lend a hand.

A story is told about Rav Michel Zilber Shlita, a world-renowned Maggid Shiur to the public, and Rosh Hayeshiva who has a special needs son. One Yom Kippur during Neilah, he was sent a message that his son had to be cleaned, and his mother wasn't available to do it. Rav Zilber went out and did what was needed. He said that he didn't know if he was doing the will of Hashem by leaving shul. However, he felt that when he cleaned his son he was doing what Hashem wanted him to do. Nobody can do it with the same loving care of a father.

The mesiras nefesh that parents have for their special children is endless. By assisting them with selfless devotion, you are filling a void that nobody could emulate. This is exactly what Hashem wants from us. Very soon we will be zoche to greet Mashiach, and those who help with holy special neshamos will stand proudly at the front of the line. ●



An Inner View

Rivky Dalfin

On the outside
It's the crutches
That people see
On the inside
Is the person
That I know I can be

When people look at me
The first thing they see
Is a girl with crutches
And inability

They think that if
something's wrong physically
Then my whole life must
be a disability
They ask how I do this
or can I do that
The comments are another thing
I need to combat

Across the board, people seem
To have low expectations
All they tend to see
Are my limitations

It feels kind of odd
When people have this view
It's kind of weird to have
People staring at you

All I want to do
Is go on a walk
But then people stare
Or they start to talk

I want to go back inside
But I have things to do
So I tell myself
To just push through

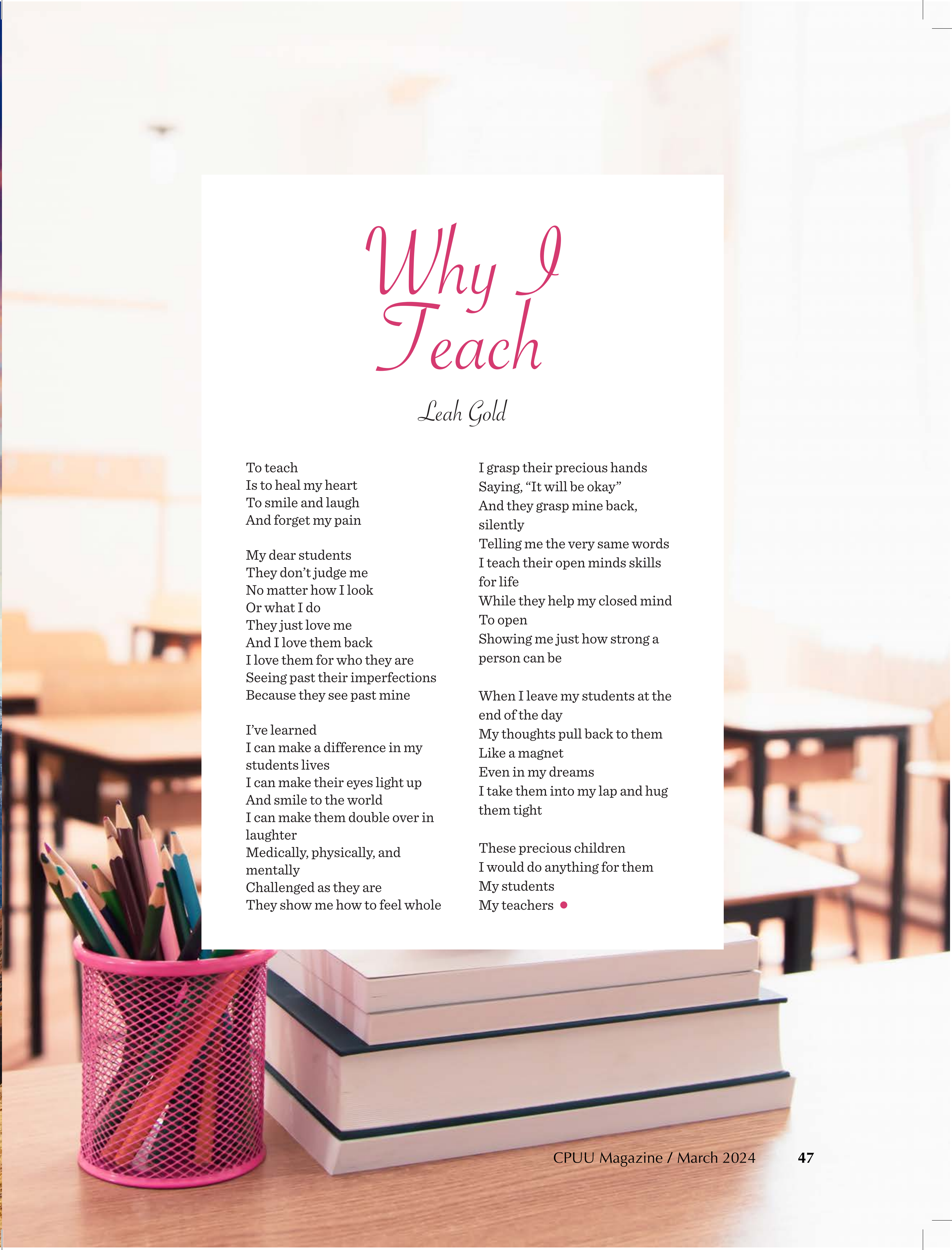
Yes there are bumps
Along the way
But overall
I'm doing great

I learned to focus
On what I can be
And not the discomfort
Of my disability

What I can be
Is an awesome me
One that is not limited
By others beliefs

With self-motivation
I can climb mountains
I can go many miles
Hundreds if not thousands

Despite the stigmatized lens
Through which others see
I will continue working
On being the best me ●



Why I Teach

Leah Gold

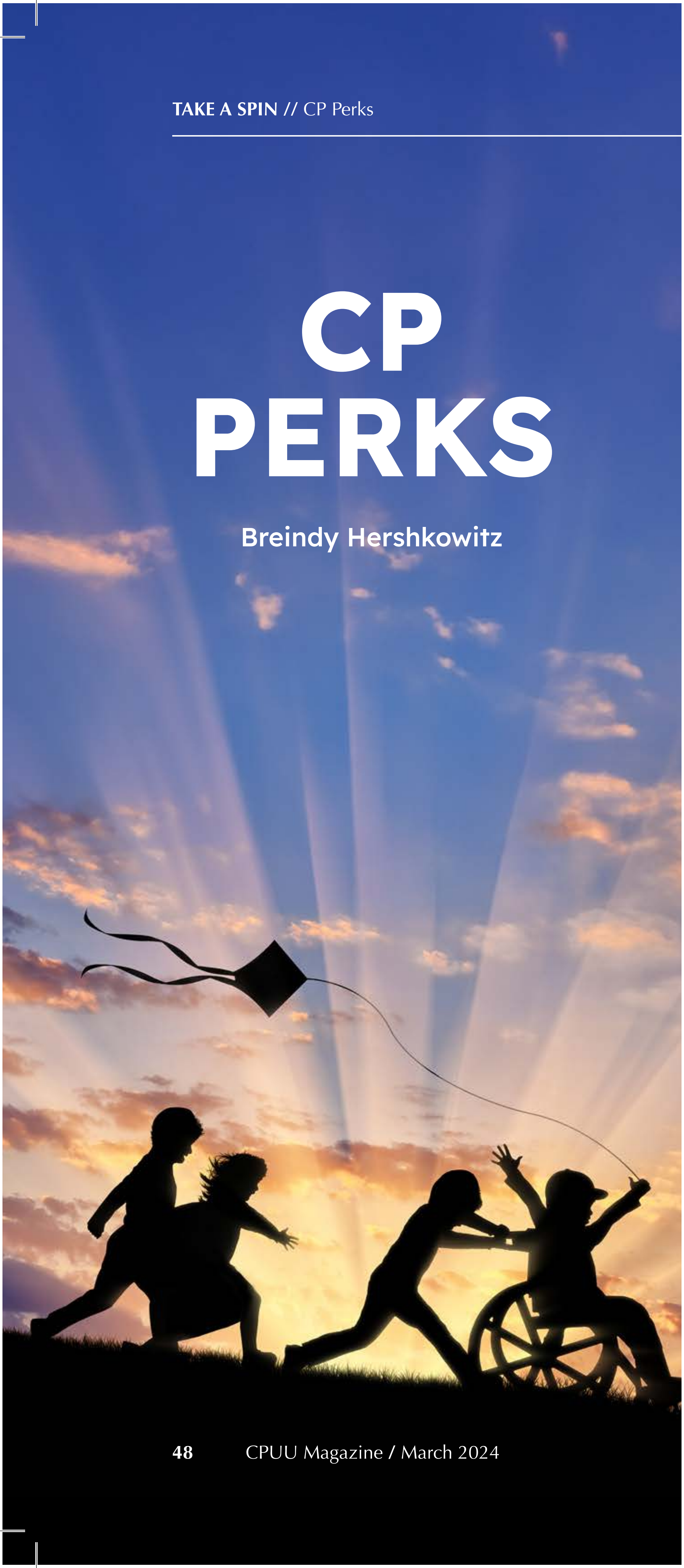
To teach
Is to heal my heart
To smile and laugh
And forget my pain

My dear students
They don’t judge me
No matter how I look
Or what I do
They just love me
And I love them back
I love them for who they are
Seeing past their imperfections
Because they see past mine

I’ve learned
I can make a difference in my
students lives
I can make their eyes light up
And smile to the world
I can make them double over in
laughter
Medically, physically, and
mentally
Challenged as they are
They show me how to feel whole
I grasp their precious hands
Saying, “It will be okay”
And they grasp mine back,
silently
Telling me the very same words
I teach their open minds skills
for life
While they help my closed mind
To open
Showing me just how strong a
person can be

When I leave my students at the
end of the day
My thoughts pull back to them
Like a magnet
Even in my dreams
I take them into my lap and hug
them tight

These precious children
I would do anything for them
My students
My teachers ●



CP PERKS

Breindy Hershkowitz

Hi! My name is Breindy Hershkowitz, and I have Quadriplegic Spastic CP. I love to have fun, and I try to never let CP stop me from doing anything. I have enjoyed traveling to Eretz Yisroel, taking vacations in Florida and California, and going parasailing. Actually, parasailing happens to be my favorite, because it doesn't depend on if I can walk or hold myself up. In amusement parks, there is no need for me to wait in line, due to my special gift of CP. Parking, too, is an absolute breeze! I am fully entitled to the easily accessible handicapped spots, and I use this privilege well! And guess what, I'm a regular person just like you, and my favorite food is steak. If someone goes out to eat with me, I enjoy steak with them, and they enjoy my good-natured sense of humor along with the food! But don't worry, my humor never hurts anyone.

People tend to give me special treatment. For example, they treat me like a two-year-old, or they treat me like I'm deaf, even though I have an abnormal hearing ability. On the same note, I am often the topic of conversation, even though I'm in the same room as the people who are conversing.

I'm lucky also, because I doubt anyone gets as many compliments on the dresses they wear as I do. I actually like to look pretty, so hey there, thanks for the compliment!

I sometimes wish I could take a loud-speaker and convey my message to the world: "People with CP have tremendous value, and their disabled bodies aren't the only thing to be focused on! We are people with personality, ideas, and thoughts, and we have our own unique opinions on things. We choose what we look at and what we don't. Even if someone does have cognitive difficulties, they deserve to be spoken to with proper dignity and respect. We are all precious neshamos, and beloved children of Hashem!"

I've made it my personal life goal to remain upbeat. Just imagine if the world would be black and white, without any color to spark joy and beauty. Imagine what life would be like, without Hashem's endless showering of chesed and kindness. He keeps giving us so much, and sometimes all we need is to open our eyes and look at the bright side of our lives. One can try and have extra kavana by the bracha of pokeiach ivrim, that Hashem should open our eyes to notice and appreciate all the good before us.

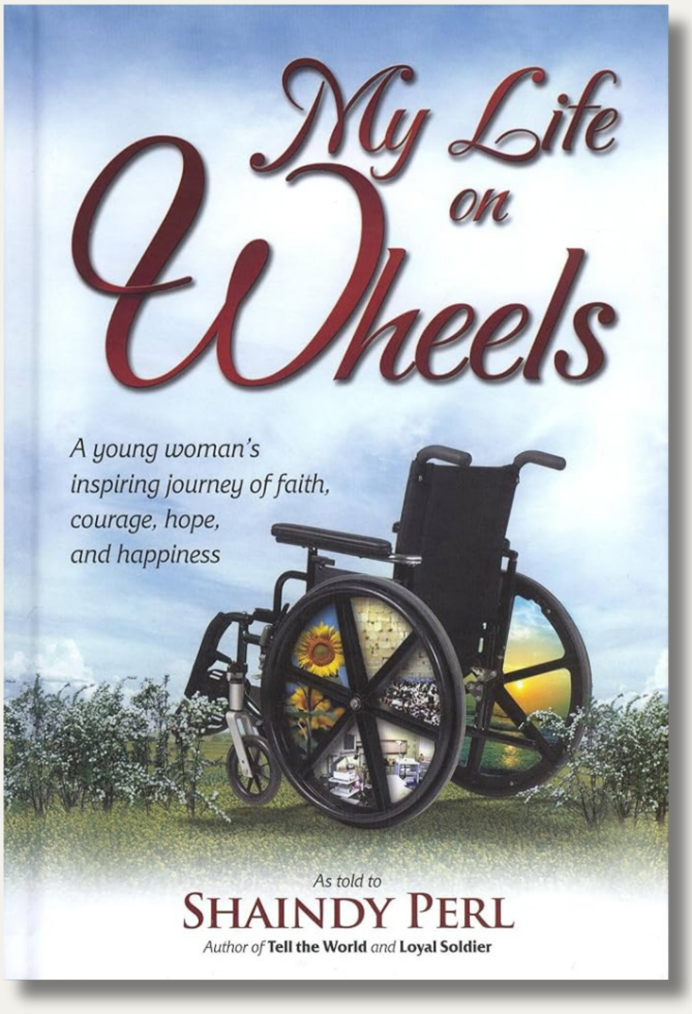
As someone who utilizes these tools, I would like to share with you what helps me in my daily challenges. If you ever feel sad, lonely, or ashamed (like we all sometimes do), just remember that our loving Father knows exactly what we are going through, even better than we ourselves know. Everything will always be okay, as long as we remember Who the One is that sent us the struggle, and Who helps us deal with it.

> **"I have CP, but CP doesn't have me!"**

Just keep this in mind for a happy productive life: "You can't choose the life you get; you can only choose your attitude!"

"I have CP, but CP doesn't have me!" ●

Breindy is the author of the book "My Life on Wheels", where she chronicles the challenges and triumphs of her life with CP.



Adaptive Clothing

Benefits & Recommendations

Amanda Vo, OT, MSOT
Biana Spektor, M.S. OTR/L

We understand that each child's needs and abilities are unique, and finding the right solutions to support their daily activities is of utmost importance. Adaptive clothing is specially designed to cater to these specific needs, offering a range of features that can make dressing and self-care routines much more manageable for both the child and the caregiver. These thoughtfully designed garments can significantly enhance your child's independence and comfort. Adaptive clothing offers:

Independence: Adaptive clothing is thoughtfully designed to enable easier dressing and undressing, allowing your child to take charge of their own clothing choices and foster a sense of independence and confidence.

Comfort and Dignity: These clothing options prioritize comfort, ensuring that your child can move freely without discomfort or restrictions. Adaptive designs also often include features like discreet fastenings and seamless fabrics that promote dignity.

Customization: Whether your child requires clothing with adjustable closures, wide openings, or sensory-friendly materials, adaptive clothing offers a wide variety of options to cater to their unique needs.

Time Savings: Adaptive clothing streamlines the dressing process, which can save valuable time during busy mornings and reduce potential frustration for both you and your child.

Inclusive Styles: Adaptive clothing has come a long way in terms of design. You'll find a diverse range of stylish options that your child will feel proud to wear, helping them express their personality and style.

Supports Social Integration: Feeling comfortable in their clothing can enhance your child's self-esteem and positively impact their social interactions, as they can focus on building relationships without the added stress of clothing discomfort.

Individuals with Cerebral Palsy often have a unique set of challenges to traverse when it comes to dressing. Body shape and position are very important factors which impact clothing choices and usage. There are many factors to consider: positions of body parts, angles of joints, range-of-motion limitations, strength, and ability levels. Adaptive clothing is thoughtfully designed with these factors in mind, as well as to accommodate individuals who also use special equipment such as gastronomy tubes, wheelchairs, leg braces, or hand braces.

Adaptive clothing offers specific elements of functionality by accommodating individuals in numerous ways. Some features of adaptive clothing and shoes are specifically designed to break through the barriers of dressing. People with special needs often have difficulty donning or doffing typical garments or taking on and off clothing. Some adaptations that address these challenges include side-opening garments, magnetic closures, special tabs to pull zippers, wide-opening shirts, tops with loose sleeves, and shortened tops for wheelchair users who want to avoid bunching. Having fasteners located in alternate positions allows for greater ease of use. There are pants with pull tabs for those who have limited fine motor abilities and wide leg pants for those who wear leg braces. Some adaptive clothing items have flat seams, do not include tags, and/or omit back pockets for easier use when sitting down in a wheelchair. Other adaptive clothing items are designed to allow for easier access to gastronomy tubes. Adaptive clothing comes in soft and stretchy fabric for ease of wear and is especially useful to those individuals who have tactile sensitivities. Adaptive shoes are sold in various widths for use with braces. Elastic laces are available for individuals who have difficulty tying laces. Most importantly, adaptive clothing is designed to increase the user's level of independence during dressing tasks, which helps build confidence and self-esteem.

One of the most fundamental benefits of adaptive clothing is its positive impact on building confidence. Imagine how independent a child can become once they are able to dress themselves. Because of all the clever adaptations, dressing can become easy and much less time-consuming. Imagine seeing your child dress on his or her own, just as their siblings do, within a reasonable time frame. Gaining independence in this way will make your child feel good about performing a task that might have been considered daunting before. It could improve their participation and willingness to make choices for themselves. They can express themselves and their individuality through the styles and types of clothing that they choose to wear. This can lead right into building independence in many other self-care tasks, such as good personal hygiene including hair and nails maintenance.

At Tiferes Mordechai Center for Integrated Learning, our therapy team places a lot of emphasis on building independence during all activities of daily living. The use of adaptive clothing has brought so many effective solutions to the lives of our students and their families. Students are able to contribute to their own dressing routines, thus making it so much easier and faster to get ready for school in the mornings. At school, they have increased their participation in adaptive sports and aquatic therapy as it has become easier to change into and out of their clothing to engage in these pursuits. Students are happier, more independent, and they look great!

Wearing fashionable clothing can facilitate acceptance for all individuals. It can lead to improved socialization, bringing people together during all kinds of activities and occupations. Adapting a variety of clothing for sports, formal occasions and especially school helps ensure participation and affords opportunities for interaction and socialization for everyone. Adaptive clothing has become more accessible and affordable. It can be comparably priced to standard clothing. Supporting companies that focus on inclusive clothing designs have further popularized adaptive clothing. Explore adaptive clothing options from various brands to find the perfect fit for your child.

BELOW ARE A FEW BRANDS THAT WE RECOMMEND:

French Toast

(https://www.frenchtoast.com/adaptive?content=hp_fsadaptive)

Lands' End

(https://www.landsend.com/search/S-xea?initialSearch=true&q=adaptive)

JC Penney

(https://www.jcpenney.com/g/baby-kids/all-girls-clothing/girls-adaptive-clothing-accessories?id=cat11100007072)

Target

(https://www.target.com/s?searchTerm=adaptive)

Kohl's

(https://www.kohls.com/catalog/adaptive-kids.jsp?CN=Feature:Adaptive+AgeAppropriate:Kids&icid=sl-nav-adptve-clothing-total-kids&kls_sbp=75501679275827065761808560183037641722)

Tommy Hilfiger USA Adaptive

(https://usa.tommy.com/en/tommy-adaptive?gclid=ff913779660814e752e35376ab2a30a9&gclsrc=3p.ds&&cid=cpc_bing_us_bau_adaptive-branded-text_adaptive-branded-all_adaptive-clothing-unisex_1321613900808056_82601169906885_tommy%20adaptive&gclid=ff913779660814e752e35376ab2a30a9&gclsrc=3p.ds&msclkid=ff913779660814e752e35376ab2a30a9)

The Charlotte Letter

(https://thecharlotteletter.com/)

SHOE RECOMMENDATIONS

Quikiks

(https://www.quikiks.com/)

Friendly Shoes

(https://friendlyshoes.com/)

Billy Footwear

(https://billyfootwear.com/) ●

Amanda Vo, OT, MSOT, is a licensed Occupational Therapist in New York State and has been specializing in the pediatric population since she graduated from Columbia University in 2021. She currently works with children who have disabilities at Tiferes Mordechai Center for Integrated Learning and does research for Open Style Lab, a non-profit organization dedicated to making clothing accessible to people of all abilities. She can be reached at amanda@openstylelab.org

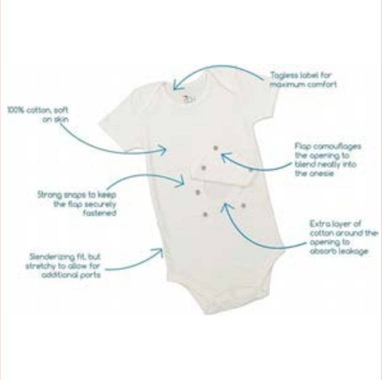
Biana Spektor, M.S. OTR/L is a licensed Occupational Therapist in New York State who has been specializing in pediatric therapy and Sensory Integration Dysfunction for over 22 years. She is currently the Clinical Director at Tiferes Mordechai Center for Integrated Learning, a school for students with special needs. She can be reached at Biana@Tiferesmordechai.com

ADAPTIVE JACKET

Available on Amazon or thecharlotteletter.com
Boys/girls, sizes 4-16, $25

ADAPTIVE ONESIES

Available on Amazon, Etsy or starberrykids.com
Sizes 1-10 (12-78 lbs.), $25



CUSTOMIZED SUIT

Hidden zippers at the seams of the suit. Simply put it on as if it's a vest, and just zip it up.

This is very helpful for stiffness in muscles, as the zippers make it so easy to get dressed.

This idea is amazing! The adaptive suit looks like any typical suit. You'd be surprised at how well these very helpful zippers are hidden!

This suit was customized at Fino Custom in Monsey, 845.613.3466.

Fino Custom | Custom Men's Clothing in New York and New Jersey.

BILLY SHOES

Available on Amazon, Etsy, Target, DSW, Nordstrom Rack, or BILLY Footwear
$30-$50

HELPFUL TIPS FOR DRESSING

Coat dressing: Before transferring the child into his transport chair, lay the coat on the back of the chair. It's easiest to dress a child in their chair while he's sitting supportively, as opposed to trying to juggle him and the coat.

Sleeves: Putting the sleeve onto the child's arm on the side of the child's tighter side is easiest. Stick your arm all the way into the sleeve, then take hold of his/or hand, and guide the arm through, while pulling the sleeve all the way on.

Skirt/pants: When putting on a skirt or pants, roll the child onto his side, to have more space to pull up the garment. If the child can make a bridge with his legs, ask him to do that for ten seconds, so you can have an easy time pulling up the garment. (This is good exercise for your child, while you're at it.)

Zippering: For children with hand function, hooking a key binder ring to the child's zipper is a great tip. This allows the child to have an easier time with gripping and handling the zipper. Companies like Tommy Hilfiger sell coats with magnetic coat closures so the child can do it on his own.

Shirt dressing: First dress the child with the other garments, leaving the shirt for last. It's easiest to put a child's shirt on while he's sitting in his chair, since gravity is working with you, and the child is supported and balanced.

Leg braces/orthotics: Have the child sit in his chair for better grip. The caretaker should sit on the floor, as this will give better control of the child's legs and will enable the caretaker to be on the same height level as the child's legs. Additionally, flexing the child's foot and rotating it in a slight circular motion, which stretches it a bit, will help the brace go on smoothly.

Yarmulkes: There are two great products that are helpful in preventing yarmulkes from slipping off. Clips can be sewn on the inside of a yarmulkes, such as Keep-Kippah or Kippah-It On! The Kippon is another helpful product that keeps yarmulkes on. Kippon is a Velcro strip which has a self-stick backing. These items can be found at Judaica stores and on Amazon, or elsewhere online.

Onesies: Using a onesie for your child will prevent the child's stomach/back from showing during transfers. Large sizes for bigger kids are sold on Kohl's, CBO, Wonsie, Special-need-products.com, adaptiveclothingshowroom.com, and other sites.

Buying clothing: Buy one size larger, for an easier time with dressing and undressing. This will also help with garments that would otherwise ride up.

Your Take

We asked our readers: Share a piece of advice or tip(s) that you would've wanted to know earlier. Here are your responses.

Did you ever think of the fact that a big percentage of children with cerebral palsy suffer from epilepsy? That affects a lot of their progress in the long run. NYU conducts a program called FACES. I was actually there this past winter and gained lots of knowledge about epilepsy in children with cerebral palsy. If you need any additional information, I can be contacted through CPUU Magazine.

IIIIIII

Children with CP may understand a lot more than it seems at first glance and on the surface level.

IIIIIII

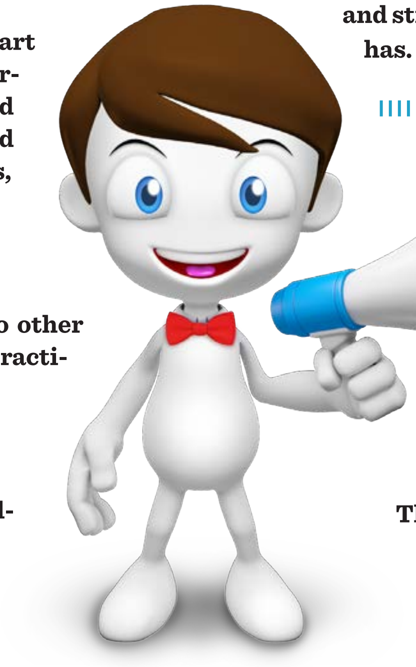
To take care of myself and start being a mommy and not a therapist. To giggle and cuddle and enjoy my child as a person and to stop noticing her muscles, just cuddle.

IIIIIII

Be in the know. Reach out to other mothers and be in touch for practical and emotional support.

IIIIIII

To explore the options available to children with CP, including SSI, CDPAP, Access-A-Ride, and grants.



I used to think, "Are there any mothers out there who have a child with brain injury? Or is it just too embarrassing?" If only I would've known that one day, there was going to be a wonderful magazine out there called CPUU!

IIIIIII

Do not overdo physical therapy sessions to the point of torture for your child. Respect your child and recognize his needs. Communicate with him regarding his own wants and consider them when scheduling physical therapy sessions.

IIIIIII

When my child does something that seems unnatural, he's just doing it to handle the sensory input and stimulus in his world with the tools that he has.

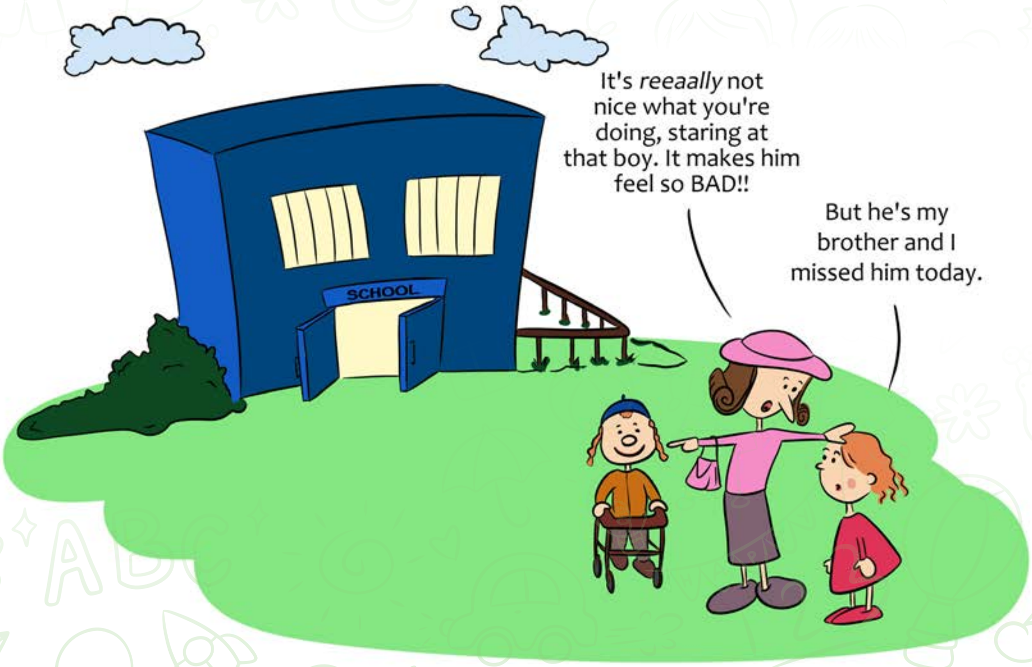
IIIIIII

Therapists can be obtained through different agencies, and you don't have to wait for your service coordinator to help you. You can and should get ideas from other parents.

IIIIIII

There is help for obtaining transportation to and from medical appointments. Medicaid should be contacted to assist with this concern. ●

Cartoon Corner



info@vividcreations.co