

# נשמהלה Neshamale magazine

*Sharing Our Special Experiences: Chizuk & Inspiration*



**Sibs  
Spot** /12

**HOW I FOUND OUT THAT MY  
SON WAS REALLY AN ANGEL /6**

*One mother's journey from birth to diagnosis*

תש"פ // CHANUKAH EDITION ISSUE #1

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Neshamale magazine welcomes your contribution of articles, poems, personal experiences or any material that may inspire our readers. We also request your comments, suggestions and donations. Please contact us if you are interested in the opportunity of sponsoring the next issue.

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**In honor of Avrumi's 4th birthday**

Avrumi, we are so proud of you!  
We love your delicious smiles!  
May you continue to grow and  
bring us tons of nachas!

Love, Your Family

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Dear Readers,

Welcome to the first issue of Neshamale Magazine! We are so happy to join with you, our fellow special parents and families, in exploring the unique mission that we share: raising our special “neshamales” with pride and joy!

I imagine that you are wondering how this magazine came to be? It is just about four years since the birth of Avrumi, my delicious boy with special needs. There have been so many emotions over the past few years: feelings of joy, hope, sadness, resignation, love, disappointment, pride... but one of the overwhelming feelings has been loneliness. The feeling that we are stranded on an island, alone with our delicious, delightful, yet challenged, child. Every day brought more questions: practical questions, emotional questions... I felt like screaming: “Is there anyone out there who can throw me a lifeline?” Actually, I know there is! I see them as they drop their children off at my son’s school. I meet them in the shoe store, the doctor’s office, the park... but I’m tongue-tied and hesitant. I don’t know how they will react to a stranger tapping them on the shoulder and talking about this sensitive topic.

I turned to reading material, as I am a voracious reader. I devoured books and articles. But there’s really not that much out there, especially of Jewish content. In desperation, I ordered a secular magazine geared to Special Parents. I opened to the table of contents and read: 5 Ways to Help Children with Sensory Challenges Participate in Halloween Festivities; 7 Easy No-Carve Pumpkin Decorating Ideas; Avoid the Halloween Candy Blues; Cooking With Kids: Spooktacular BOO BARK Breakfast Yogurt; 10 Halloween Safety Tips for Children with Special Needs; List and Explanation of Disabilities for Disability Awareness Month. That was it. Disappointed, I threw down the magazine without reading a single article. There’s got to be a better way, I thought.

A week after the magazine fiasco, in conversation with a friend, she remarked, “The challenge of raising a child with special needs is unfathomable to someone who does not have it.” Something about this comment bothered me, although I wasn’t sure exactly what it was. After all, I didn’t disagree. Then I had another conversation with a different friend that clarified things. I had called this friend, who had recently given birth to twins, to see how she was managing. She told me that the babies were both behaving beautifully and she was getting back to herself. “How are the other kids doing?” I asked. “Actually, that is a good question!” she remarked, “Everyone offers me help for the twins, but I’m having a harder time with my seven-year-old son!” “I totally understand you,” I said. “I also get offers to help out with Avrumi (my special needs son), but sometimes I need more help handling his siblings!” To which she responded: “It’s not really the same thing. I am happy to have the twins as an excuse to get help, but you are not happy about having Avrumi and getting these offers.”

I realized something startling at that moment: People think I’m not happy about having Avrumi! They see him as a “challenge,” a “tzarah”! This could not be further from the truth! Now I realized what bothered me about my first friend’s comment – it was the words “unfathomable challenge” with no mention of “unfathomable joy”! Why is my friend so sure that her twins are a bracha and my child is not? He is one of the most joyful, blessed parts of my life!

I am not here to sugar-coat the realities of raising a special needs child. Of course, it’s challenging. In some cases, it’s downright grueling. But it’s also inspiring and rewarding. In some homes the joy comes from the gorgeous smiles and adorable things our children say. In other homes, the joy has to come from a deeper place: the purity and the beauty of the special neshama itself. And for all of us, there’s joy in the knowledge that Hashem chose us and trusts us to host and raise His precious child.

I have no complaints against my wonderful friends for not understanding. It really is unfathomable to them. But not to you, dear readers! There’s no reason to feel alone when so many of us are traveling the same route. Although every family’s experience is unique as can be, there is so much we share in common. Feeling part of a group has the power to hoist us over the waves, saving us from going under.

To satisfy my craving for a good read on one of my favorite topics, combined with my search for support, I’ve created “Neshamale,” a magazine full of inspiration, education, tips, and positivity, to connect with all of the other “hand-picked by Hashem,” heroic families out there!

The goal is to generate a feeling of camaraderie, hope, joy, and inspiration, and to share lots of practical tips, advice, and humor! This is not my magazine; it’s “ours.” Please join in the conversations, send in your experiences, your “view,” the tips and advice you worked so hard to figure out on your own. Sharing is caring.

Welcome, and enjoy!

## דברי ברכה

### מאת הרב דוד שוסטאל שליט”א ראש הישיבה בית מדרש גבוה לייקוואוד, נ.י.

I would like to give divrei chizuk to my dear talmid and yedid nefesh, R’ Raphael Tawil, his rebbetzin, and all who are involved, for undertaking the publication of this magazine. “Neshamale” will bring encouragement and inspiration, and also a great help in disseminating information to parents who were chosen by Hakadosh Boruch Hu to have hoiche, heilge neshamos in their midst, to bring them to their ultimate tikkun. We need to appreciate these parents, as they are doing a service to Hakadosh Boruch Hu on behalf of Knesses Yisroel, to fulfill the full medreigos of these heilge neshamos in Knesses Yisroel, and to bring us closer and closer to the ultimate geulah shleima b’karov didan, bimhera b’yameinu amein v’amein. Hakadosh Boruch Hu should give the worthy misaskim in this holy undertaking, all of the parents, and all of Klal Yisroel, the zechus to speedily be zoche to be mekabel pnei moshiach tzidkainu bmheira b’yameinu amein v’amein.

# How I Found Out That My Son Was *Really* An Angel

One Mother's Journey from Birth to Diagnosis

By: Gitty Weiss

## *Mazal Tov! It's a Boy...*

When Dovy was born, it seemed to be that the only difference between him and his four older siblings was that he didn't nurse. He didn't take a bottle either. He screamed from the moment he was born, almost straight for the next six weeks. The only reprieve was when he was tightly swaddled in his car seat in a dark room, when he would sleep for a few hours at a time. But I knew that a lot of babies cried and didn't eat well. I thought that I had just been lucky with my older ones; I wasn't too concerned.

Until the day after he came home from the hospital, when he developed a fever. We went back to the hospital, underwent a myriad of tests, got inconclusive results, and were sent back home. While we were in the hospital, Dovy's temperature was regulated in an incubator and he received an IV to supplement my futile nursing attempts. That's why he stabilized and was sent home. As soon as we got home, his temperature started fluctuating and he stopped eating. I spoke to the pediatrician and we came to the (correct) conclusion that his temperature had nothing to do with being sick; it was a result of dehydration and malnutrition.

Loathing a return to the hospital, we tried everything possible to remedy the situation at home. I tried feeding our son around the clock. We tried every kind of bottle and every kind of formula. I saw countless lactation consultants, all of whom walked in super-confident and walked out super-confused. He didn't have a latching problem and he didn't even have a sucking problem. He just didn't want to eat!

Every few weeks it got so bad that we ended up in the emergency room and were admitted for a few days. The IV would help and we'd be sent

home. It was a ridiculous cycle with no answer in sight. My baby kept losing weight. He looked terrible. Finally, at 5-1/2 weeks of age, we checked into CHOP (Children's Hospital of Philadelphia) and said: "We're not leaving until this is figured out!" They decided to try reflux medication, even though Dovy was so young and did not have the classic signs of reflux. Two days after starting a high dose of Omeprazole, he drank his first bottle and kept it down! He stayed in the hospital for five days until they were sure that his weight gain was finally picking up.



*Dovy at 5 weeks the day before going to CHOP*

We brought our baby home with instructions to feed him 1.5 ounces of a special high-calorie formula every two hours. The feeding took 45 minutes. That left 1 hour and 15 minutes for the rest of our lives. This went on straight through the night, with my husband and I taking turns feeding him. It was an incredibly tiring and overwhelming schedule. Dovy hated the bottle and we basically had to force it down. But as soon as he started the medication, he stopped screaming in pain and started smiling.

## *A Happy Baby*

As the weeks passed and he slowly gained, one ounce at a time, we were able to give larger feedings with more time in between. As Dovy grew, he became cuter and happier. I had never seen such a joyful baby before. He literally laughed with delight throughout the day! Occasionally, the thought crossed my mind that maybe he

was too happy, but who complains about such things?

Dovy was a very quiet baby. He did not babble or coo. He was also very sensitive. Light and noise bothered him. He didn't like to be held. In fact, it was almost impossible to hold him. He would go so rigid from my touch that he was like a stiff board sliding out of my arms. When I would put him back into his car seat, his favorite spot, he would laugh joyfully.



*Less than a month later,  
Dovy is gaining weight  
and smiling*

As cute and as smiley as he was, Dovy was not really progressing past the newborn stage in terms of physical development. I felt that there was something off with his eyesight. We took him to an eye doctor who diagnosed him with strabismus, nystagmus and foveal hypoplasia (an underdeveloped retina). We were very shaken to receive this diagnosis. It was unclear exactly how severely his eyesight was affected but it sounded serious. I pictured him in school, using a large print Gemara and struggling to make out the words. I davened fervently that it shouldn't affect his learning, his social status, or his ability to drive, work, and function normally. Little did I know what we were really up against.

Once Dovy was officially classified as “visually impaired,” I had him evaluated for early intervention. I assumed, and all of the therapists agreed with me, that his rough beginning in life, as well as his visual impairment were what was causing his delays. I also suspected some kind of sensory processing disorder, as he was so sensitive to so many different things. I thought I was being overly pessimistic when I told myself that he may have to be in a special setting for a few years until we work out all of his little issues.

Early intervention started when Dovy was seven months old. The first therapist who entered my home was an Occupational Therapist (OT) with years of experience. I confided in her that I was unsure whether his delays could all be blamed on his vision impairment, that perhaps there was something more serious going on. She held Dovy and observed him very carefully for an hour. She saw how he startled very easily, was so hard to hold, and refused to go on his stomach. She did all kinds of tests on him, trying to ascertain his abilities. Finally, she looked at me and stated confidently and resolutely: “There is nothing wrong with your son. His vision is confusing him and making the world a scary place for him. His hearing is ultra-sensitive and he has to learn how to tune out the background noise. He has a lot to learn but he will be 100% fine. He is normal!” I was so relieved, I wanted to hug her! The assessment of this experienced therapist, who had worked with hundreds of special needs babies, brought me a lot of (misplaced) reassurance. He had many sessions each week: OT, PT, vision therapy, and DI, all in our home. We also took him out of the house for extra OT and feeding therapy, his biggest needs at that point. It was very hectic but it was Ok. As long as he would be Ok, we were Ok too.

### ***Is Something Wrong?***

Between his age of 7-12 months, we were in a busy, yet calm, routine. But when Dovy turned one, the therapists got frustrated and confused

with the very little progress they were seeing in all areas. Yes, he had a late start, and yes, he had a vision impairment, but why wasn't he getting anywhere?

All the specialists we saw agreed that Dovy was normal, yet delayed. No one had any real answers. One of our concerns was that the back of his head was very flat. His severe reflux made it painful for him to have “tummy time” and we thought this was causing the flatness. We took him for cranial therapy, which consisted of his having to wear a special helmet to gently round out the back of his head. He hated it, and it didn't work anyway. No matter which way the technician set it up, his head remained as flat as ever.

Dovy was 9 months old on his first Simchas Torah. I was upstairs in the ladies' section, looking down into a sea of black hats and suits. Amidst the crowd, I saw my tiny baby, with whitish blond hair, a face shining with joy, and an angelic smile. I remember thinking to myself: “He looks so holy, he can't be a normal baby!”

Right after Yom Tov, we had a well visit to the doctor. Our pediatrician is a wonderful, involved doctor who really takes the time to listen and care about each child and issue. He was very worried about Dovy, which was very worrisome to me, because his general attitude is to be laid back. As we discussed my son's developmental delays, the doctor handed me a referral to CHOP's genetics testing. “I want you to have him tested,” he said. “Usually when there's a lot of little problems, it means something is really not right. I'm not sure, and I hope I'm wrong, but we have to look into it.” I took the paper, put it in my purse, and got ready to leave. I had one foot out the door of the exam room, when I quipped, “What

is it called when a baby is so cute and yummy and laughs all the time?” I meant it as a humorous rhetorical question but my doctor wasn't laughing. He said thoughtfully: “Actually, there is a syndrome like that. I learned about it years ago in medical school. It's called Angelman Syndrome.” That was the first time I heard the words that would change our lives.



*Dovy at eight month old*

He said “What is it called when a baby is so cute and yummy and laughs all the time?” I meant it as a humorous rhetorical question but my doctor wasn't laughing. He said thoughtfully: “Actually, there is a syndrome like that. I learned about it years ago in medical school. It's called Angelman Syndrome.” That was the first time I heard the words that would change our lives.

He left the room and came back holding a thick textbook. He turned to the page titled “Angelman Syndrome.” There was a checklist of characteristics describing the syndrome. I started reading aloud: “delayed development, severe reflux as babies, problems with movement and balance, happy demeanor with frequent laughter, short attention span, fascination with water, unusually fair skin with light colored hair, small head with a flat back...” as I read, I was getting so excited that we had figured it out! Everything on the list fit Dovy to a “T”! Then I got to the last line, which read: “Severely limited intelligence.” I froze. I looked up the doctor and said confidently: “No. Dovy does not have severely limited intelligence. He's so smart. He's so social. It can't be.”

Being the wise doctor that he is, he did not argue with me at all. He just nodded and said: “Ok, so it's not this. But make an appointment, because it's something.” I walked out of the doctor's office sure that my son did not have Angelman Syndrome.



Believe it or not, I really wasn't worried. I was so sure that Dovy was "normal." That night, I mentioned the doctor visit to my husband and then went to sleep in blissful ignorance. Little did I know that it would be my last peaceful night for a while.

### *Is Dovy an "Angel"?*

The next day I was sitting at work, bored. On a whim, I googled "Angelman Syndrome." Although my computer has a filter that blocks just about everything, the clipart/images are not blocked because we use that for work. I suddenly found myself looking at a screen filled with pictures of dozens of faces: blond faces, smiling faces, special needs faces...faces that looked exactly like Dovy. The room started to spin; I was literally shaking in my seat. At that moment, I knew without a doubt that Dovy had Angelman Syndrome.

After a few minutes, I came back to myself enough to bottle up my fears and feelings, and continued work on auto-pilot. Somehow, I made it through the day, drove home, and explained to my husband what I had seen. I called the pediatrician. He didn't seem too surprised to hear from me. "Do you really think this is it?" I asked, hoping he would reassure me. "We can't know anything for sure. Make an appointment," he advised me.

Next, I called my mother. "Ma, do you think that something could possibly be, like, really wrong, with Dovy?" I blurted out when she picked up the phone. A long silence. Then a very cautious voice: "Well, I mean, you know that something is wrong, you just don't know what, right?" "NO, I do not know that!" I screamed in panic. "Do you mean to tell me that you think something is really wrong?" I felt so, so dumb at that moment. It dawned on me that maybe many people had realized this, and I alone had been walking around in a happy, clueless bubble! Just for the record, I am a very realistic, practical person, not the type of mother who thinks her kids are always perfect and can do no wrong. For some reason, Hashem "blinded" me until the moment that He decided it was time for me to find out the truth. In hindsight, I appreciate that I got to know and love my baby before I knew anything was amiss. But the shame and guilt was hard to swallow.

The first night "after," I was so worn out emotionally that I fell asleep surprisingly quickly. But when I awoke at 4:00 am, there was no falling back asleep. Visions of handicapped children danced in my mind. The questions taunted me: Was Dovy retarded? How would we deal with him? Maybe he's fine. He has to be fine, he's so cute and normal! My thoughts swirled around in agonizing circles. Finally, I got up and went to say Tehillim. And that's where my husband found me at 4:30 in the morning, when he woke up and couldn't fall back asleep!

The next morning, I called CHOP Genetics and explained that I wanted to bring my baby to test for Angelman Syndrome. The receptionist was shocked. "I have never had such an unusual request. How did you even hear of this syndrome and why in the world do you think your child has it? This is not something that most people are familiar with; certainly not able to diagnose on their own!" I explained

how my pediatrician had thought of it and how it seemed very likely to me. "Ok, dear, we can see you on April 17th," she chirped, as she prepared to hang up the phone. "April?" I exclaimed, sure that she had made a mistake. "Yes, dear, that is our next available appointment." It was October 15. "Do you mean to tell me that I have to wait six months to find out if my son has Angelman Syndrome? Do you mean to tell me that I won't be able to sleep, eat, or live for the next six months with this hanging over my head?" She apologized and suggested that I call back each week to ask for a cancellation.

I did just that, and two weeks later landed a cancellation for a few days later. The first appointment consisted of taking many measurements, filling out piles of paperwork, and drawing blood. The doctor himself told us that Dovy did not present as a typical Angleman kid, but it was still a likely possibility. We were told to expect a call with results in about eight weeks.

### *The Hardest Weeks of My Life*

It was ten weeks from the day that I saw those pictures until the day that the diagnosis was confirmed. Ten of the hardest weeks of my life.

Some days I was positive that Dovy had Angelman's. Other days I convinced myself that he just looked like those pictures because he was so fair and blond and had a cute goofy smile. We could not settle down and get used to the new situation. The way to move on is to accept, but we didn't know what to accept! We were filled with fear for the future and had many, many questions.

We reached out to the Angelman Syndrome Foundation and they mailed us some reading material. The printed information was not very encouraging. It seemed that "Angels," as we learned they are referred to, have significant delays in all areas, especially expressive language. We were busy educating ourselves about something that we weren't sure even applied to us.



*Dovy at 16 months, shortly after being diagnosed*

We were given a psak that since the results were still hidden, we could and should daven for a good outcome. My husband's rebbe had connections with someone in Eretz Yisroel who could go in to HaRav Chaim Kanievsky shlita, and we asked him to get a bracha that Dovy should be healthy and well. This man explained the situation to Rav Chaim, who responded (in Hebrew): "He will be a tremendous source of nachas, and it will not be repeated in their future children." My husband derived three conclusions from these words: that Dovy would have Angelman Syndrome, that we would have at least two more children, and that it would not be hereditary. (In a small percentage of cases, Angleman Syndrome can be hereditary.) Thus far, all of the Gadol's predictions came true.

In the meantime, my older son's upsherin was coming up. I threw my energy into making him a great party and tried to enjoy the simcha. I was tempted to call CHOP to check if they had Dovy's results, but I forced myself to wait until after the upsherin.

The very next morning, I bravely picked up the phone and dialed.



# WHAT IS ANGELMAN SYNDROME?

“Hello, CHOP Genetics.” “Hi, I wanted to know if you have any test results for my son Dov?” I was told that the results were in and that the nurse would call back shortly. I waited tensely, afraid that they would tell me to come in to discuss it in person, worried they would not tell me anything over the phone. I felt I could not handle the suspense for another minute; I davened for them to have pity on me and tell me the results immediately. The nurse called back a few minutes later. “The bloodwork shows clearly that your son is definitely missing the ube3a gene on the 15th chromosome. This means that he does have Angelman Syndrome,” she said in calm, yet sympathetic voice.

With all that preparation, you'd think I wouldn't have been so shocked. I guess nothing can prepare you for the moment when you hear that your life has changed forever. When I heard those words, I felt so weak that I had to grab onto the fridge handle to keep myself from falling over. I think the nurse continued talking and explaining, but I heard nothing. I tried to steady my shaking, weak self and somehow hung up. I took a few deep breaths and felt a strong inner voice screaming at me: “This is an eis ratzon – don't waste it!” So I mustered up all strength I could and whispered: “Hashem, I know this is a test from you. I accept it with love.”

## *Moving On....*

“Accepting with love” sounds great. It's actually a lifetime of hard work. I'm the type of person who likes to do things quickly but there were no shortcuts here. I had to start from the bottom and make my way up, step by step. I walked around the whole day, and lay in bed at night, just repeating over and over in my head: “Dovy has Angelman Syndrome. I have a special child.” I felt like I just had to drill it into my psyche, that the sooner I got used to it and accepted it, the better off we would all be.

I remember calling my mother a few days after the diagnosis and asking her: “I feel like 90% of my mind and heart are with Dovy all day and I have about 10% left over for my other kids, my husband, and every other part of my life. Will it always be this way or will I get over it?” Somehow, my mother always knew just what to say to me. I could not have gotten through that rough period without my entire family's full support.

Receiving the diagnosis myself was almost easy compared to what came next: letting everyone else in our lives know about it! I first had to tell my husband about the phone call. Then I had to tell my parents, my in-laws, my siblings, my friends, my co-workers, and every one of Dovy's many teachers and therapists. Each conversation took its emotional toll. Every time I said the words, “Dovy has Angelman Syndrome,” it was like a knife plunging into my heart. But every time I said it, the pain dulled a tiny drop at a time. It took a long time for those words to roll off my tongue in the nonchalant, painless way that they do today.

Telling people about the diagnosis meant that I had to deal with their reactions. Some of those who found out were shocked by the severity of what we were dealing with. Most had never heard of Angelman Syndrome and asked questions about what his abilities would be. For some reason, I think that a more common diagnosis is easier for others to hear about, even if it's not really any better, than a scary sounding, unknown name. Others were not surprised at all, as they had suspected something of this nature from knowing Dovy.

Angelman Syndrome affects males, females, and all ethnic groups equally. There is an estimated 1 in 15,000 births.

Dr. Harry Angelman is credited for having discovered this genetic disorder in 1965. Before that, thousands of cases were misdiagnosed as cerebral palsy, autism, or other disorders.

In most cases, Angelman Syndrome is caused by abnormal function of the gene UBE3A, located within a small region on chromosome #15.

The main characteristics of those with Angelman syndrome always include: developmental delays, speech impairment, ataxia (balance disorder) and a uniquely happy demeanor with frequent laughter/smiling.

Other characteristics that are sometimes seen include: seizure disorders, strabismus, feeding problems during infancy, tongue thrusting and excessive chewing behaviors, increased sensitivity to heat, diminished need for sleep, scoliosis, constipation, and obesity in older children.

Some physical characteristics that are common include: small head circumference with a flat back of the head, hypopigmented skin with light hair and eye color, and a wide mouth with widely spaced teeth.

Research indicates that educational and behavioral intervention has been shown to be effective in the areas of communication, education, sleep disturbances, and general behavior. Physical, occupational, and speech therapies are important methods of intervention. Alternate communication techniques are very useful for individuals with Angelman Syndrome, as their receptive language ability is greater than their expressive ability.

(The Information here has been obtained from the Angelman Syndrome Foundation)

## Resources:

### *Angelman Syndrome Websites:*

[www.angelman.org](http://www.angelman.org) (USA), [www.angelman.co.il](http://www.angelman.co.il) (Israel), [www.angelmancanada.org](http://www.angelmancanada.org) (Canada).  
There is a newsletter called *Angelman Today*, at [www.angelmantoday.com](http://www.angelmantoday.com).

I went very easy on people. I thought to myself: "How would I react if I was on the other side? I would not know what to say!" Almost everyone just listened sympathetically to the news, and told me how much they loved Dovy and would continue to love him. That was the main thing I needed to hear, that he would be accepted by those around him, unconditionally.

The strangest part was that, practically, nothing had changed at all! How could it be that our world had turned upside down, yet everything inside of it remained the same? I thought about how a family would react if they had just received a cancer diagnosis, *chas v'shalom*. Before they even had time to absorb the shock, they would be in the hospital, meeting specialists, dealing with insurance, and davening their hearts out for a good outcome. Contrast that to our situation. Here, I felt that my life had been altered in a huge way, but actually nothing looked different. Dovy was the same yummy, smiley baby. He continued to receive exactly the same therapies. He stayed in the same playgroup. Our schedule stayed the same.

The changes were all internal. The hoping and davening that had filled my life during the past ten weeks had to be redirected. Instead of hoping for an easy way out, we would hope for Dovy to be the best "Angel" that he could be. My tefilos changed from: "Let it be good," to: "Let me accept and see the good."

### ***Where Are the Tears?***

One thing that bothered me was that, during this entire *tekufa*, I never shed a tear. Not a single one. I felt pent-up with emotion and the need to cry it out. I'm sure some people wish they could just stop crying, but I felt like everything was stuffed inside of me with no way out.

A few days after receiving the diagnosis, I was driving to work when the song "Come with Me, Little Neshamale" was playing on Abie Rottenberg's Journeys CD. I listened carefully to the words and was blown away. I had heard this classic song many times before, but I now saw and heard it with a different perspective.

I pictured Dovy's neshama up in Shamayim, the Malach telling him his unique mission in the world: to live a life of limitation and handicap, to live in a body unable to do many things--not even mitzvot. I pictured him worried and confused: "How will I do my tefkid?" he wonders. And the Malach tells him: "This is how! Your job is to live the life we are giving you. This is your way to stay holy. You will not even have a yetzer harah!" The main thing that struck me is that Dovy IS A REGULAR NESHAMA. Does that sound obvious? Well, when we are so busy focusing on the "specialness" of our children, we sometimes forget that their neshamos are just that -- a chelek of Hashem with a mission, just like you and I. I pictured his neshama coming back up to Shamayim after 120 years, still shining and pure, and being let free... In Olam Haba, he will not be "different," he will be "normal" -- a neshama that fulfilled its tefkid in this world.

Right there, driving in my car down Ocean Avenue on the way to work, the tears finally fell. But they were not tears of pain; they were tears of *nechama*.

---

*The author is using a pen name. She can be contacted through Neshamale Magazine.*

Neshomele

Abie Rottenberg Journeys II

Come with me, little Neshama'leh  
And let me hold you in my hand  
And we'll fly away, you and I together  
To a place down on the land.

Come with me, little Neshama'le  
Don't shy away  
Do as you're told  
There's a little child waiting to be born today  
You're to be his spark, his soul.

But dear Malach'I, no!  
I don't want to go!  
There is so much much pain and evil  
Upon the earth below.

Let me stay here up in heaven  
Where it's safe and I'll be pure  
Please don't make me go away  
Can't you see I'm so afraid?

Come with me, little Neshama'le  
It's time you faced your destiny  
And as we fly beneath the clouds now, I will show you  
There is so much you can be

Yes, dear Malach'I, I can see kedusha over there  
There's someone learning Torah  
There's another deep in prayer.  
I will stay here if you answer me  
It's all I need to know  
You must promise me, my dear friend  
That I, too, will be like them.

Come with me, little Neshama'le  
Oh, it's a task that I must do  
As I tap you on the lip, you will forget me  
You're on your own  
It's up to you.

(interlude)

Come with me, little Neshama'le  
And let me hold you in my hand  
And we'll fly away, you and I together  
To a place above the land.

But dear Malach'I, no!  
I don't want to go!  
I'm not ready to go with you  
Where you take me I don't know  
Let me stay right where I am  
There's so much more I need to do  
Please don't make me go away  
Can't you see I'm so afraid.

Come with me, little Neshama'le  
I've only come to take you home  
And there is no need to fear your destination  
You've earned a place right by the throne  
A place right by the throne.



# From The Doctors Desk

## | *What to Expect at Your Genetics Appointment*

Sarah Raible, MS, CGC

Clinical Director, Center for Cornelia de Lange Syndrome & Related Diagnoses

Senior Genetic Counselor, Division of Human Genetics

Childrens Hospital of Philadelphia (CHOP)

### **What to expect during your visit:**

The goal of a pediatric medical genetics appointment is to review your child's overall health and determine if there is an underlying genetic etiology contributing to your child's health differences. During your appointment you will first meet with a genetic counselor. Genetic counselors are trained healthcare professionals with expertise in medical genetics and counseling. The genetic counselor will begin by reviewing the pregnancy, birth, and medical history of your child. In addition, the genetic counselor will ask about your family history and draw your family tree. He/she will likely ask about the health of other individuals in the family and if anyone else has developmental delays, autism, birth defects or other medical conditions. Next, a medical geneticist will perform a physical exam of your child and may ask additional questions. At the time of your visit, the genetics team may be able to tell you the reason for your child's symptoms. Most of the time, genetics tests are needed to determine a diagnosis.

### **What is genetic testing and how is genetic testing done:**

There are many types of genetic tests and your geneticist may recommend one or more tests after your evaluation. Genetics testing is typically done through a blood test, though sometimes a different kind of sample may be needed such as skin, saliva, or a cheek swab. The turnaround time for results varies depending on the type of test; however, genetic test results take longer than routine blood tests due to the level of complexity that is involved with the analysis. In general, the turnaround time for genetic test results can be anywhere from a few weeks to a few months.

### **What happens after you receive results:**

If a genetic diagnosis is found, your genetics team can often give you information about the condition and any medical treatment options.

There are several benefits to finding an underlying genetic answer or diagnosis that explains your child's symptoms. Finding answers for families serves many purposes:

A diagnosis can end a diagnostic odyssey and eliminate the need for additional procedures and tests which can be stressful and painful for the child and family.

When a known genetic diagnosis is identified, families are given information about prognosis and medical management guidelines.

Finding answers allows for accurate recurrence risk counseling and testing of other at-risk family members if appropriate.

Finding answers also allows families to identify other individuals with the same diagnosis to form a community that is invaluable for support and advocacy.

Lastly, finding answers helps to understand the natural history of a diagnosis that will eventually lead to improved medical management with the ultimate goal of establishing therapeutics.

*If testing does not reveal a genetic cause and the etiology of your child's symptoms remains unknown, it is recommended you follow-up with your genetics providers every few years as new testing and new information becomes available.*

Q

## IN SESSION

Dear Shira,

I have a three year old with severe special needs. Until now, most people didn't realize what was going on as my son looked like a regular baby. Recently, I have gotten a few offers for help. I truly need the help but I am having a really hard time accepting it. I am so overwhelmed, wishing for someone to help me; but when they call, I end up declining out of embarrassment.

I feel like I should be able to take care of my own kids. I also feel guilty sending him out with strangers, although he doesn't seem too upset about it. When he does end up going out, I feel so sick about it that I don't even enjoy the break! How can I accept the help in a positive frame of mind and make this a good experience for everyone involved?

Nechama L.



By: Leah Tawil, SLP

You have it in you to help your child open his mouth, so to speak, and enable him to communicate.

Here are some tips to incorporate even more communication into what you are already doing during your day. Try to establish predictable routines throughout your day which naturally present built-in communication opportunities.

**Getting dressed:**

Sing a song each day that includes the articles of clothing. It can be any tune, but here is one idea:

(TTTO: "Here we go 'round the Mulberry Bush")

"This is the way we get (child's name) dressed, get child dressed, get child dressed... so early in the morning... First we put a shirt on his tummy.... then we put the pants on his legs... then we put the socks on his feet... so early in the morning."

Once your child learns to recognize the song, see if you can get him to take a 'communication turn'. Start to pause at different places in the song and wait. Perhaps your child will stick out a hand or foot to put in the clothing, or he will vocalize. Any small initiation on the part of the child should be interpreted as a 'turn', and should be rewarded with lots of verbal praise.

A

Dear Nechama,

Thank you so much for your courageous and honest question! Asking for help can mean losing independence and control, and is extremely difficult. Most people feel that when they ask for help it feels like they are "less than," incompetent, and/or unworthy. Having to take care of any child requires an immeasurable amount of work, time, and effort, and a child who has special needs requires a lot more.

A woman can be compared to a well from which one draws water. However, a well only works if there is water in the well and it is of good quality. Think about the amount of water drawn from your well when you take care of your child. How are you replenishing it? When you get help, your well will be refilled and there will be more for this child and for other family members.

Here is an interesting, contradictory concept: When you say "no" to something, you are saying "yes" to something else. Think about it:

When you say "no" to help, you are saying "yes" to feeling overwhelmed, incompetent and not being able to cope. Which do you want to choose?

Don't underestimate the benefits the giver is getting. She might be finding fulfillment, connection and meaning to her life. This experience might be an equal give-give opportunity. Moreover, the power of your child's pure neshama can fill her heart and give her innumerable benefits she may not even realize.

**Think again: Who is giving and who is getting?**

Wishing you much nachas from this child and the rest of your family,

Shira Speiser, LCSW

*Shira Speiser is a Social Worker in Lakewood, New Jersey and has helped children and families for many years. You can contact her at 732-367-1503*

# SPECIAL PARENTS

# *of* SPECIAL CHILDREN:

By: Chayala Tawil

## *A Talk with Rabbi and Mrs. Gruen in Los Angeles, CA*

My earliest memory of meeting a child with special needs was back when I was a young girl. I grew up in LA, where the Gruen family were our neighbors. They had a handful of adorable boys, a few of them with special needs. I was fortunate to get to know most of the lively crew! I was always inspired by the way Rabbi and Mrs. Gruen were patient, smiling, and full of energy.

Now, years later, as a parent of a child with special needs, I remembered this with clarity and called them up to learn their secret.

Rabbi Yaakov and Mrs. Miriam Gruen were happy to share their simple, yet profound words of wisdom.

Rabbi Gruen began: "It's very hard to accept, at first, but in the end, you shteig from it."

Mrs. Gruen added a more practical note, advice they got from an understanding friend: "You can't look past your nose! Take one day at a time!"

Rabbi Gruen then shared a positive perspective, saying: "You come to appreciate things that easily go unnoticed. If you want to experience the positive, you need to recognize those things that get taken for granted and be grateful for all the details. For example, at our son's bar mitzvah, when he began to lein maftir, I suddenly experienced a deep, emotional feeling of sheer joy and gratitude. Our child has the ability to do this! The challenges help keep us focused on what really matters."

"There is an important point that is often hard for parents with young children to hear," Mrs. Gruen continued, "If Hashem wants to make a neis, we welcome any yeshua. Of course Hashem can do anything. But we shouldn't run to every new program, every segula, new doctor, new diet, magic potion. Our children are who they are and we have to accept that."

"When we brought our toddler to the psychologist for the first time, he explained to us that disabled children have limitations, possibly 70% that of a typical child. With all the support and therapy we could give him, he may reach that potential of 70%, but there are so many variables that may prevent him from reaching even near that. Our children will be disabled as long as Hashem wills it. They may be 'higher functioning,' but they will not be cured."

"Will you spend your life trying to find that elusive cure or will you accept and live your life with joy? Of course, you should try to find the best classes, teachers and therapists. But don't let it overtake you and your family. There are so many things out there – diets, methods, and

who knows what – that can distract you and more importantly, can wreak havoc on your family. The most important thing for your child's well-being is your menuchas hanefesh. Your state of mind will affect those nearest and dearest to you. Remember to take care of yourself so that you can take care for your loved ones, especially your husband! Don't lose your shalom bayis. If you are bentched with additional children, you need to enjoy them as well; they also need your

undivided attention. Whatever help you can get, take it. For the sake of your child, for the sake of your family and most importantly, for your sake. As they say: "If mama ain't happy, ain't nobody happy!"

Rabbi Gruen concluded: "Enjoy your children, they have a special chein, just enjoy them!"

As I thank the Gruens and say goodbye, I remember all they went through to ensure the best care for their special children. I am inspired by their wise words, gleaned from over 20 years of experience raising their children. While I understand that, for each family, 'doing the best we can' will look different, I am thankful for my glimpse into these amazing parents.

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*The most important thing for your child's well-being is your menuchas hanefesh.*

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## The Spaghetti Surprise

Tova  
Finkelman  
age: 10

"Avi, Avi!" we all called out. "Where are you?" Avi is a cute, smiley boy who gets lost all the time. Whether he's in the bathroom throwing his toys into the toilet, or hiding in the laundry room under piles of laundry, he's always up to some sort of adventure. It gets hard to find him when you think of all the places that a skinny two-year-old boy could hide! So, on this particular day, Avi was missing once again and the search was on.

"Maybe he's in the bathtub," Dovid yelled. "I'm going to check outside, maybe he went onto the porch!" little Shevy shrieked, as she ran down the stairs. I was looking for him, too. "Where could he be?" I thought. "Maybe he's in the kitchen?" I screamed out. "We already checked there," Binyomin groaned. He was curled up on the couch reading another freaky comic book. Binyomin was the only one who was not running around looking for Avi. He never got too involved when it came to Avi. Not when he got lost, and not even when he did something cute and everyone made a big deal about it. But Binyomin's attitude wasn't going to stop me!

I dashed through the hallway and stopped short at the entrance to the kitchen. There he was, sitting quietly on the floor, covered in spaghetti! I burst out laughing. Spaghetti was everywhere! It was tangled in his mop of curly hair and twisted between his thin little legs. He looked hysterical, slurping up gallons of spaghetti and giggling quietly, with a big empty bowl beside him.

The whole family came rushing in and laughter filled the kitchen. Even Binyomin had peeled himself off of the couch and was smiling at the scene. Everyone got on their hands and knees to clean up the mess. My mother dumped Avi into a warm, bubbly bath. Our favorite supper was gone, but on that day, everyone felt a special loving connection with Avi, the most mischievous, but cutest, boy in the world!





# Activity Time!

Here is a fun activity to do with your sibs on a rainy Sunday afternoon. Or even as a nice Chanukah after-supper activity...

## Supplies:

- 1 jar/container per child (We used washed-out baby jars)
- Decorative materials, like permanent markers, stickers, tiny pom poms, etc.
- Small strips of paper (Colorful is always more fun!)
- Pens

## Directions:

Each child decorates his jar with his name and designs. When everyone is ready, pass the jar to the person to the right. Look at the name on the jar and think about something nice about this sibling. Write it down on a small slip of paper. Fold it up and stick it into the jar.

Repeat steps 2-4 until everyone has written something about each sibling.

Now everyone has a treasure chest of compliments from some of the best people in their life!

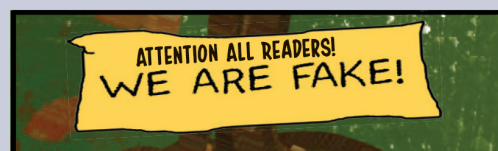
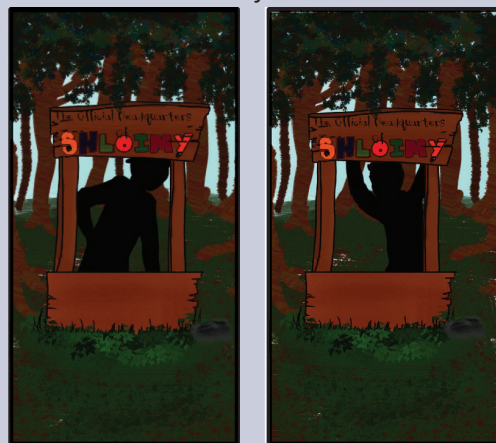
## Variations:

Depending on the abilities of your special siblings, they should be included as much as possible. Have them sit around the table with you and pass around the jars. If they can talk, ask them what they want you to say about each sibling and write it down for them. You will feel so good to hear what they say about you! Of course, everyone should write a compliment for them, too. Make sure to read the notes aloud to your special sibling when you are done! Even if they don't understand all of the words, they will feel your love!



## Meet Shloimy

By Elisheva Dickstein



# Upsy Downsy

My name is Meir. I'm twelve and a half, and I live in Yerushalayim. I'm popular and not bad in school.

It's taken me a while to tell my story, and soon you'll see why. But because I think lots of kids have gone through the same thing, I'm going to tell it.

It started four and a half years ago, when I was eight.

I had a friend named Menachem. We saw each other every day, because he lived on my block. Menachem didn't go to my school, yet he was one of my very best friends. Our fathers davened in the same minyan, and we played outside and in each other's houses.

One day, Menachem told me he had a new baby brother. I said mazel tov and was happy. Then I asked him when the bris would be.

Menachem said that he didn't know yet, because the baby was slightly unwell so they couldn't make the bris right away.

"You'll tell me, okay?" I said to him.

Menachem promised to tell me.

Eight days passed, then two weeks, a month – and still no bris. Menachem said that the baby had heart defect and that until he had an operation, they couldn't make the bris.

I asked him what the baby's name was so that I could daven for him.

Menachem laughed. "How can he have a name if he hasn't had a bris?"

"You're right," I said. "So what do you do?"

"My parents asked Rav Chaim Kanievsky, and he said that we can daven like this: 'Harach hanolad ben Sarah.'" (Sarah is the name of Menachem's mother.)

That's what I did. Also, I wrote "Harach hanolad ben Sarah" on the blackboard in my classroom, and everyone said

tehillim for the baby's health, not before I explained to them the reason for the strange name.

After three months, the baby had an operation. A month after that, they made him a bris and he was named Yosef. I wasn't invited to the bris. It took place in the hospital. I was beginning to understand that the story with Yosef, Menachem's brother, was not simple at all.

But I still didn't know then just how not simple.

One day, Menachem said to me, "You haven't been to my house in a long time."

"You're right," I said. "Your house hasn't exactly been the same since Yosef was born and had to be in the hospital."

"Well, now we're finished with all that. He had the operation, and he's completely healthy, and now life is back to normal."

I went to his house, partly out of curiosity, because I wanted to see the new baby. I waited in the living room and Menachem went into the bedroom to bring the baby.

I heard a sound, and there was Menachem walking into the living room pushing a new carriage. I ran over to see the baby.

The minute I looked at the baby, I understood everything.

His eyes were slanted, he stuck out a long tongue, and I didn't need to think too much to realize that Yosef was a child with Down syndrome.

It was one of the most difficult moments in my life. It wasn't the first time I'd seen a child with Down syndrome, but I'd always felt sorry for them and their family. And now, all at once, I found out that my friend Menachem had a new baby brother with... with Down syndrome.

I wanted to cry. I felt very uncomfortable. I didn't know what to say. I'd never been so uncomfortable in my life.

As if that wasn't enough, Menachem said to his mother, "Mommy, can I hold him?"



Menachem's mother took Yosef out of the carriage and handed him to Menachem. Menachem held him carefully and brought him close to me.

"My mother lets me hold him," he said proudly. "Look how cute he is."

Menachem put the baby's face near mine. Little Yosef looked at me and stuck out a long tongue.

Menachem rolled with laughter. "Did you see his tongue? That shows that he likes you. He always sticks out his tongue at someone he likes, don't you, Yossi?" Menachem started to kiss Yossi over and over again until his mother said, "That's enough. You're smothering him with love."

I didn't know what was going on here. Menachem had just told me that the baby had Down syndrome, so why did he look so happy? He was glowing and seemed proud to show me how the baby moved his head and gave a Down syndrome smile.

"Do you know what we call him?" Menachem asked me. "Upsy Downsy, because Yossi is the cutest baby in the world. He's not down, he's up, and I'm crazy about him. Everyone is."

"Yeah...I'm sure," I said, even though I was sure of the exact opposite.

There were some very uncomfortable moments, because it was obvious that Menachem wasn't happy at all. He was only pretending to be. That's how I felt. Naturally, I didn't say anything about it to him. I pretended to be excited and happy too.

About ten minutes later, I told Menachem that I had to go. I didn't really have to go, but the whole visit weighed on me like a ton of bricks. I felt terrible that something like that had happened to Menachem and his family.

As for the happiness they showed, I didn't buy it.

I ran home and told my mother what had happened to Menachem's family. In the middle, I started to cry, releasing all the tension I'd kept inside.

My mother didn't know Menachem's family except to say hello, but she'd heard that they'd had a Down syndrome baby.

I told her that Menachem seemed happy and even proud of Yossi, but it looked to me like he was faking it. It was impossible for someone to be happy about a baby like that being born to his family.

"Actually," my mother said, "I've heard that they're very cute

children and very lovable. I'm not sure Menachem is just pretending."

I felt like my mother wasn't convinced of what she was saying.

But the story doesn't end there. It took on a twist I could have never imagined.

Half a year later, my mother had a baby girl. I'll never forget that morning. My father came home and told us that we had a new baby sister. He didn't look happy, though. He said that the baby had a few problems.

"Problems?" I said. "What kind of problems?"

"She has a heart defect."

A heart defect...I immediately thought of Yossi.

"Abba, is it only a heart defect? Or is there something else?"

My father looked at me. I saw he was trying to decide what to say.

"It's a heart defect that children with Down syndrome often have."

I felt a chill.

"So our new baby has...Down syndrome?"

"It looks that way," my father said, trying to soften the blow. Then he added, "Meir, I'm going to need your help. We'll tell Shira and Motty (my sister and brother), and I need you to give them a good feeling about it, so they won't be scared."

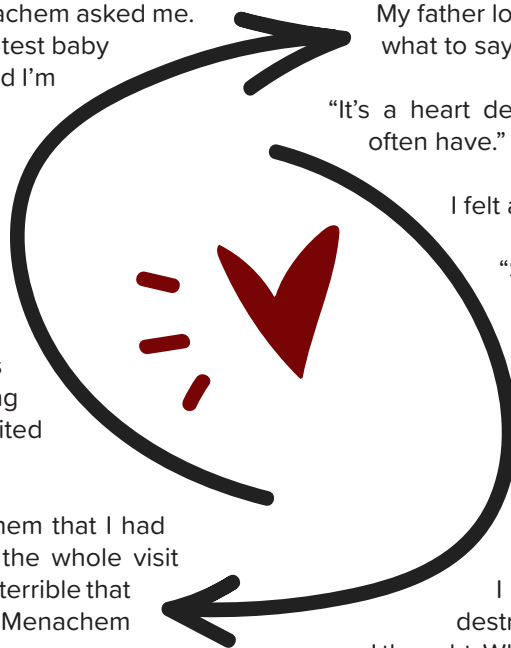
I closed my eyes. I felt like my life was destroyed. I have a sister with Down syndrome, I thought. What can I do with that? How will people look at me? They'll probably all feel sorry for me. I was terrified.

"Meir, it's okay. Hashem chose us to raise this soul. He must think good things about us. I need you to help me tell this to Shira and Motty in the best way possible."

You'd be surprised, but the fact that my father asked me to help him shook me out of my depressing thoughts. I pulled myself together and went with my father to Shira. I did exactly what my father had done with me. I got her to join me.

"You know that we have a new baby," I said to Shira. "She has a heart defect, but G-d willing, she'll get better."

Shira was a little bit happy, and a little bit worried, but I calmed her down.



About an hour later, I said to her, "It could be that the baby has Down syndrome."

"Really?" Shira said, and she started to cry.

"We have to tell this to Motty," I said, "but not in a way that he'll get scared. Look, my friend Menachem has a baby with Down syndrome, and they really love him and they're so proud of him. Let's go tell that to Motty."

And that's what we did. Together with our father, we told Motty that the new baby most likely had Down syndrome.

Motty was only six and didn't really understand. He looked at the three of us and saw that we looked pretty happy (at least we pretended to be), so he realized that he could be happy too.

We didn't say anything to three-year-old Tali. What would she understand?

\*\*\*

Racheli – that's the baby's name – came home after a week and a half. It was love at first sight. She was cute and sweet, though not so healthy. She needed a heart operation, so she was a little weak, but that just made us love her even more.

She was the center of attention, and we all wanted to help feed and diaper her and just plain watch her.

One day, Tali was watching Ima dress Racheli when she suddenly said, "Ima, why does Racheli have Down syndrome?"

My mother couldn't believe it. No one had told Tali anything about it. "How do you... Why do you think she has Down syndrome?"

"Don't you see?" Tali declared almost scornfully. "I guess you don't know, but we have a girl in our preschool who has Down syndrome. I saw right away."

My mother started to laugh and then came to tell us. We smothered little Tali with hugs and kisses. That broke up the last remaining tension we had.

Racheli's operation was a success, and she was soon back home, healthy and whole. All of a sudden, we realized what a gift we'd been given.

I know you don't believe me, the same way I didn't believe Menachem. But it's really true: Down syndrome kids are the sweetest. They're so happy and lovable.

Racheli brought tons of joy and laughter to our home, warmth and love that you can't even describe. She's a kid who laughs and smiles all the time and tries to make everyone happy and get them to laugh.

We all hug her and kiss her and just eat her up, we love her so much.

When friends come to me or when I take Racheli for a walk and show her off to everyone, I know exactly what everyone is thinking. They're thinking that I'm just pretending.

But I don't care, because I know the truth. We received an amazing gift that made our whole family much happier, more cheerful, and better than we were (and even before, we were like that, but now even more so).

I had to get this present in order to understand that Menachem wasn't pretending. What I saw on him was exactly what everyone sees on me. I love Racheli so much, and I'm so happy with her and proud of her. She's the most amazing human being, the happiest and the most full of love.

You won't believe it, but we're not willing to part with her for even a minute. Even when we go on vacation and we could leave her with close family members who offer to watch her, we don't want to. She's our Racheli, the pride and joy of the family, and we don't want to miss out on being with her.

Racheli is already four and goes to a regular preschool. The girls love her, because she loves them. Kids with Down syndrome are so warm and friendly, that people around them just give it right back to them.

So if you see a family with a child who has Down syndrome, you should know that you've met a very happy family. You don't need to feel sorry for them (or be jealous, which is forbidden). Kids with Down syndrome are very lofty souls, and it must be that Hashem thinks good things about families that are blessed to have them, and that's why He gave them this present.

In our family, we don't say "Down syndrome" anymore.

We have a different word, one that's perfect for our Racheli and all the boys and girls with Down syndrome: "Upsy Downsy."

Dedicated to Racheli, my very own Upsy Downsy!

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*Thank you to Feldheim Publishers for allowing us to reprint this story from Kids Speak 8 by Rabbi Chaim Walder.*

# What Would You Do?

If you are having a friend from school come over and you don't think they know your special sibling yet, do you tell them anything in advance? Would you say anything once they are in your house and meet him/her? Why or why not?

Shira, 8: I don't tell my friends, but it would be smartest if I did. Once a friend left when she saw my brother. If they were in the house and my brother would not be able to hear, I would tell them.

Dovid, 13: I do tell my friends because I don't want to shock them!

Eli, 9: I tell them so they shouldn't be surprised! I am proud of my brother!

Yakov, 9: I tell my friends before they come because I want them to be aware of it. If they came and I hadn't told them, they might not feel comfortable because I hadn't warned them.

Yossi, 6: I tell them so they should know that we have a not-normal kid in the family and they should know he may be annoying and ruin their things and they should be nice to him.

Tehila, 7: I'm embarrassed, so I don't say anything. If they ask questions when they see him, I just try to change the subject.

Shevy, 10: I think my brother is cute and I don't mind anyone knowing. Anyway, my whole class already knows!

Question for next issue:

**If you had five minutes to speak to your special sibling and they would understand everything you said, what would you want to tell them?**

Please send in your answers to Sibs Spot! We can't wait to hear from you!



# Why? ME?

By: Rabbi Ezra Klein

I knew it immediately. One look at her eyes and facial expression was all I needed. Our worst fears were confirmed. Our newborn daughter had Down Syndrome. I only half-listened to the doctor give a scientific explanation as to how she had the signs of a child with Trisomy 21 (the medical term for Down Syndrome), as if calling it a different name would make it easier for us to digest. Only a blood test could confirm it, he added, saying that it would take a full week until we had results. I didn't need a blood test. "Down Syndrome" was written all over her face. I walked over to my wife, wondering how to break the news to her. She looked at me and said calmly: "I know. You don't have to tell me." She had also seen her. And she had also heard what the doctor said. Looking back, I see that this was just one example of the many kindnesses the Ribbono shel Olam did for us. Since that time, I have never seen my daughter look so much like a child with Down Syndrome again. It was easier knowing and learning to accept it right away than harboring false hopes for a week until we received results from the blood test.

We had been told there was a chance of our child having Down Syndrome when they took a sonogram during the pregnancy and found that she had a "hole" in her heart, called AV Canal defect. That news was bad enough. They assured us that in 95% of the cases, surgery when the baby was about 6 months old would repair it permanently. But AV Canal is common in children with Down Syndrome, the doctor added, insinuating that there was a chance this baby might have that condition. There was no procedure available to repair that, though! The only way we stayed sane at that point was by constantly reminding ourselves of one thing: Hashem's in charge. Worrying will get us nowhere. The doctors are not in charge. Neither are we. Only Hashem will decide what will be the future of our unborn baby.

My own research at that time taught me that less than half of the children with AV Canal have Down Syndrome. I reasoned that if so, we could definitely rely on the "rov," the majority, and assume that she would be "normal." We also received brachos and assurances from rabbonim which we understood to mean that even her heart defect would be better by the time she was born. And we davened. Boy, did we daven! We also asked others to daven for us. And we hoped. Honestly, we just didn't think we were the "type" of family to have a child with Down Syndrome. It didn't fit. We also didn't think we were really up to the task anyway. So Hashem wouldn't give it to us. We had it all figured out. But we were wrong. There she was, making a face that was unmistakably a "Down face." Now what?

We had to deal with our own feelings, our children's feelings, and our relatives' and friends' feelings. We experienced a tremendous chessed from Hashem with Nechama being born on the eve of a two-day Yom Tov. We drove to the hospital right before Yom Tov began. We then had two full days without the phone ringing, without many neighbors coming, without dealing with others' reactions. This gave us the crucial time we needed to sort out our own feelings. The hospital was within walking distance to our home, so even though I walked home each day to spend time with my children, I was still able to spend a considerable amount of time with my wife. We talked a lot. We cried a lot. Not cries of despair or mourning; rather cries of the overwhelming emotions we were dealing with. We asked a lot of questions. And with Hashem's help, we came up with some answers.

As soon as we were told that our unborn baby might have Down Syndrome, we were shocked, of course. Our entire future, which we looked forward to, and had plans for, seemed to have changed. We felt that this child would need a tremendous amount of time and effort from us, her parents. Raising our other children was already a full-time job for my wife, as well as a part-time job for me. How would we manage? Would we be forced to "neglect" our other children? What would happen to all of our other responsibilities?

Additionally, and more importantly, we were bothered by the question: Were we up to the task? Was this new role too much for us to bear?

To make sense of our predicament, I realized we needed to get back to basics:

What is our purpose in life? Why did Hashem create us?

Hashem doesn't need us. He didn't create us for His needs. Creating us was an act of kindness. He created us to give us an opportunity to grow and perfect ourselves so that we should be able to enjoy olam haba, forever and ever.

But, what is our personal unique purpose in coming to this world? This is a popular question that many people grapple with. What should we focus on, develop and pursue? Wouldn't it be nice if we had a navi to guide us as to what to devote our energies to?

People usually look for something spectacular to accomplish, like saving someone's life, donating a building for tzedakah, or writing a famous book. I personally always felt that the question was overrated. We have a Torah with many different mitzvos. Hashem created us and he gave us the Torah. He is telling us that the way to fulfill our purpose is by adhering to the Torah in its entirety. We are all unique individuals with different personalities, families and upbringings. No two people are exactly alike. My mitzvos are not your mitzvos. Hashem wants my mitzvos. That's why He created me and that's my special purpose in His world.

Nevertheless, there may be special deeds or accomplishments that are reserved for me alone. How do I figure out what they might be?

After our Nechama was born, I realized that pondering this question is often a waste of time. Hashem Himself actually tells us our purpose very clearly. How? He puts us into situations that we have to deal with. And then we know; that's our purpose. It's that simple. My and

my wife's purpose in life is to take care of Nechama and make sure that she succeeds as much as she possibly can. That's not to take away from the fact that we have other purposes, which are just as important. We also have a spouse, other children and many other mitzvos. Our purpose is to take care of all that, too. Yes, it's challenging when we can't seem to do all of them and we have to choose which one takes precedence in any given situation. But, this struggle to make the right decision is also part of our challenge and part of Hashem's master plan.

But why this challenge? Why can't we grow with the "normal" challenges of childrearing that everyone else has? Why do we need to be stressed out, not knowing what to do next, and not having the time or energy to do what's next, even if we knew what it was? In other words, WHY ME?? Why can't I have a "normal" family?

Let's go back to the basics again. We are put into this world very temporarily for only 100 or so years. We have a job. That's to grow. Spiritually. To develop our neshama into a holy being that is able to be close to Hashem in the next world, which will last for eternity. How do we grow? Through challenges.

Rashi at the beginning of Parshas Vayeishev tells us that when Yaakov was seeking to live in tranquility, that's when the troubles of Yosef were thrust upon him. "Hakadosh Baruch Hu says: 'Isn't it enough what has been prepared for the righteous in the next world; should they also want to live in tranquility in this world?'" Of course, we understand that Yaakov wasn't seeking to have an "easy" life by relaxing and taking it easy. He would surely utilize his time for Torah and mitzvos. But Hashem said: "No, that's for the next world; this world is for challenges and troubles." That is only way to truly grow.

Hashem shows us this concept clearly in the realm of physical strength. In order to strengthen one's muscles, one needs to put strain on the muscle. "No pain – no gain." Straining the muscle induces the physiological reaction of strengthening it. Our spiritual muscles work in a similar vein.

Our neshamos are all different. We all need different challenges to grow properly. If you've ever gone to a physical therapist or personal trainer you know exactly what I mean. First, you undergo an extensive evaluation to see what needs improvement. Then you're given a specific regimen of exercises, tailored specifically to your body and its needs. As you progress, the exercises are changed to provide even more improvement to your situation. Sometime before your child was born, Hashem gave you an extensive evaluation. I don't know if it was a year before, ten years before, or maybe even before you were born. But Hashem, in His amazing wisdom, understands that you need a very specific regimen in order to grow into the great person He knows you can become. To facilitate your growth, He developed an amazing exercise machine which can exercise all the different spiritual muscles in your neshama: Bitachon, patience, perseverance, chessed, simcha and many more. It grows as you grow and the challenges get harder as you get better. It's guaranteed to last as long as you need the exercise. This is your special child. He or she is your key to everlasting bliss in the Next World by helping you (and occasionally forcing you!) to improve spiritually and to realize your full potential.

It is true, that if I had been asked, I probably would not have chosen our family as the ideal family to have such a child, especially at that point in our lives. But I don't know too many people who would have chosen to have such a child. That's just the point. We are so lucky that we don't make these choices. If we would, we would obviously have made the wrong decisions. Hashem makes these decisions and He knows us better than we do, and He knows what's best for us and what's best for this child's neshama. Now that we have a child with Down Syndrome, we know that it would have been a great tragedy for us if we would not have had her. We would have been left with much unrealized potential as human beings and avdei Hashem.

We know that Hashem is merciful and loves us greatly. He would never give us something difficult unless there was a worthy payoff. Knowing this reassures us that the more challenging our special child is, the more growth we can gain from him or her. We rest assured, knowing that if we could somehow gain what we need with less struggle, Hashem would surely have given us a smaller challenge.

Nechama was not able to have a full repair of her heart until she was a few years old. One Shabbos, when she was one year old, she was very lethargic. After consultations with doctors we took her to the hospital. There, in the emergency room, with me observing, her heart stopped and they had to do CPR. After a long while, they managed to revive her, but they didn't have much hope for her survival. Some of the medical

staff called me and my wife out of the room to ask us if we needed a "Rabbi" to help us through this difficult time, since they thought it was all over. It was touch and go for a few days, but eventually, with Hashem's help, she recovered. I remember asking the doctor afterwards how bad it had been. She looked at me, and said with all seriousness: "She was gone." I always thought of that incident as Hashem telling us that Nechama wasn't born by "accident," chas v'shalom. She is supposed to be here on this world, in our family, and it was even worth Hashem performing techiyas hamaisim to ensure that she survived.

We all need to realize that our child is here on purpose— for a purpose. He or she is the best thing that could have happened to us, and he or she is exactly what we need to ensure we realize our potential.

Many people talk about "accepting" our special children. I don't think that's a healthy approach. We need to "embrace" our child; not merely "accept" him or her. Keeping these concepts in mind will help us successfully embrace our child. Perhaps we wouldn't have chosen to have this child if the choice had been given to us before we had him. But now that we have him, we know it's just what we need. If we were given the choice now, we would surely want him, knowing that Hashem deems him to be the one thing we were missing in our lives. Once we understand that Hashem decided we need this child in order to become truly great people, we will gladly embrace him. After all, he, or she, is our key to everlasting bliss.

*Rabbi Ezra Klein is using a pen name.  
He can be contacted through Neshamale Magazine.*



# My Little Warrior.

I hear you bound into the waiting room with anticipation  
 A minute later you are standing at my desk  
 Trying to control your breathless excitement and fidgety hands  
 Can you push me on the swing and can I climb the rock wall just once?  
 Can I fill the Playmobil pool with water?  
 Can I choose my prize already?

### I want to tell you:

Climb that wall a thousand times  
 You are on top of the world  
 Take 5 prizes--maybe 10--the whole box--you deserve each one  
 Every milestone you've achieved is worth the world  
 Every disappointment and struggle is another pin on your lapel  
 Every despairing sigh another test to your perseverance  
 You, my little warrior  
 Despite every obstacle  
 Despite your struggles with self-worth  
 Despite the x's and disapproving looks  
 You get back up and fight onward.

### And with your tenacity you are telling me:

Build me with my strengths  
 Capitalize on my successes  
 Don't only focus on fixing my weaknesses  
 My lack of focus, my word retrieval problem, my poor social skills  
 Garden with me, I am a green thumb  
 Teach me about animals, I am a zookeeper  
 Bake with me, I am a chef  
 Paint with me, I am an artist  
 Use my gifts,  
 The wonderous gifts Hashem has given me  
 To build me  
 You don't need to harp on my "problems," my "limitations"  
 You just need to empower me to succeed  
 With the wonderfully perfect skill set Hashem has given me  
 The limitations I have are my crowning glory.

By: Tehila Laufer, SLP



## On the lighter side...

Raising a child with special needs includes many "laugh or cry" moments. We have had our fair share of those "moments" over the years...

My shvigger came over Shabbos morning and when I served the cholent we found croutons and soggy lettuce floating around. My shvigger was aghast but I could not stop laughing! Yehuda, my cooking pro!

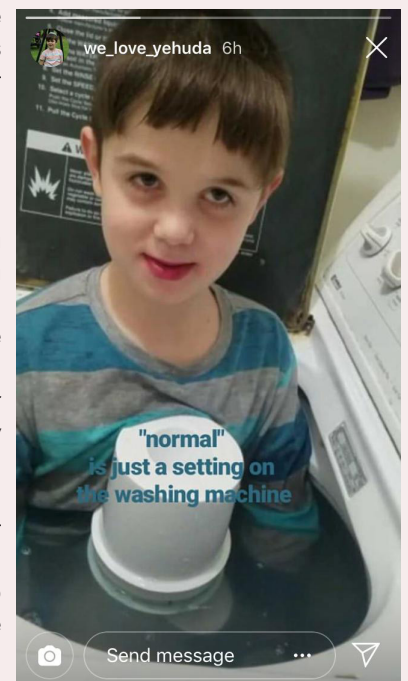
For a while, Yehuda had a shaitel obsession. How soft and fuzzy they are! One day he came down the steps eating my neighbor's sheitel that had just been freshly set for her sister's wedding. She just laughed and said: "Yehuda, you are the best!"

Ahh, the Shabbos when the soup seemed to smell a bit pungent... When I opened the pot, there were all the shoelaces everyone had been missing!

I remember when Yehuda would "borrow" shoes. He would go from house to house and "borrow" neighbor's shoes. His favorite were Mrs. G.'s Shabbat shoes. Whenever anyone found shoes outside, they always knew they belonged to us! I hid the kids' shoes in my bedroom at night to make sure everyone would have their school shoes. We would find shoes in the fridge, the cabinets...

A memory that "takes the cake" is the eggs under the blanket. Yehuda must have been terribly deficient in "Vitamin Eggs," as he would do anything to get his hands on raw eggs. My husband came home with 4 dozen eggs and he needed to hide them so Yehuda would not get them. He hit upon the best hiding spot: under his blanket. The sight of four dozen eggs cracked all over his duvet cover is something I will never forget!

The best was when Yehuda was craving a warm bath and had a grand idea. He climbed into the washing machine while it was on! How warm and cozy! I doubled over in laughter but simply could not get him out! I thought about calling the fire department, but settled on undressing him so he was able to climb out. His skin felt strange for a few days after.



Please share your hilarious moments along with pictures to [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com)



When my son was graduating from early intervention, I got each therapist a big canvas bag personalized with their name and “#1 therapist.” It came out looking great. I know that therapists already have a bag, but I figured they can never have enough bags for all their toys!  
– Miriam Baila W.

Early intervention therapists travel from house to house in the cold winter days. I gave them a thermos cup that you can plug into the car charger. They all loved it! I ordered it on Amazon for less than \$10 a piece. – Chayala

Gifting all the incredible people that are a part of helping with our magnificent treasure, Yehuda, is something that is always on my mind. I honestly wish I could give them all gift cards every Rosh Chodesh, but with nearly 70 helpers, I just can't do it. I printed labels through Oriental Trading co., which I put on boxes filled with small perfumes. For the teachers, I gave a beautiful letter with a picture of my son and a chocolate bar. I've given Slurpees to the neighborhood kids, along with a thank you note and a picture of Yehuda. – Fraydel

If the main teacher has kids, I have given toys. I have also given towels; really anything nice and practical is appreciated.  
– Sara Levy

In honor of my son's birthday, I wrote a nice poem and brought the teachers muffins and iced coffees for breakfast. I also bought a new toy for his classroom. – Esther

A picture with a chocolate bar. Who doesn't like a good bar of chocolate? – R.N.

When I didn't have too many people to give, I got hadlakas neros match boxes from a gift store. I wrote a stunning letter about how when they light candles and daven for theirs', the work they've done with our children will be a zechus. I remember one therapist calling me and saying that she never cries but this letter had her crying! – M.F.D.

For me, it's the card that's most important. The more personal, the better. – a Speech Therapist

A gift certificate to a restaurant is a nice idea for a teacher. For girls, I bought lucite jewelry boxes or or lucite makeup containers and they loved it! You can also give a cloth makeup bag with their name embroidered on it.  
– Sara T.

I try to send in small things at random, unexpected gift times. It means a lot more than when you send at Chanukah or Purim. When I have time, I bake; when I don't have time, I buy a small chocolate platter. It is not expensive and it means the world to them. Aside from showing Hakaras Hatov, it is really for your child's benefit! – C.T.

Every time my son was hospitalized, I came with candy platters for the nurse's station. You would not believe how far some gummy bears can go in making you popular! The nurses are so overworked and this makes them feel appreciated and gives you a bit more individualized attention. Keep some extra trays handy at home so you can grab and go if need be. – Eli

## Tips From The Experts *hey! that's us!*

**We all have many people in our lives who work with our special needs child and deserve our appreciation. From the teacher to the therapists, from the volunteers to the nurse in the hospital, what are some nice, affordable gift suggestions?**

Question for the next issue:

**What is your “mantra” or one-liner that helps you keep perspective and ride the waves when things get stormy?**

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

# Smart & Safe

## In the kitchen

Making our homes “Smart & Safe” is a big project for those of us with talented, persistent, and creative children with special needs. This is a topic close to my heart, as I have my own special child, Yehuda. Obviously, safety is a priority, as is maintaining our sanity. For me, it’s imperative that our precious Yehuda can be safe in our home without constant supervision. Although I often pay the price for his freedom, I am confident that overall, B”H, our home environment is safe for him.

In this column, I hope to share my ideas and advice on how to make each room of the house what I call “big kid proof.” As each child and situation is unique, not all of my ideas will necessarily work for you.

In this issue, I will focus on the kitchen. The kitchen is usually the center of a Jewish home and is thus a major area in need of safety and sanity. The easiest solution would be to simply lock up the kitchen, but this is usually not feasible! In the meantime, here are some tips on what worked for us.

### FRIDGE AND FREEZER

This is important for those of us who want the food we made for Shabbos to still be there to serve on Shabbos! My fridge bears witness to the many standard locks I purchased in the baby-proofing section of local stores. They are very simple and easy to purchase, install and use. Here, however, is what to use when they all fail:

#### 1 Refrigerator Door Lock (without padlock) - White (\$16.95 on Amazon)

This lock is said to be permanent, and in our experience, it has been. We’ve had ours for a few years now.

We secured it with a combination Master Lock, which we find to be long-lasting and smooth, and doesn’t jam like others brands we’ve tried.

#### 2 Master Lock 653D Locker Lock Set Your Own Combination Padlock (\$5.68 on Amazon)

A lot of the large deep-freeze freezers have a key, which has worked well for us, too. Just be careful not to lose the key!

### OVENS/STOVES

I have tried many oven locks and they all failed. Either they were too easy to open or they did not attach to the oven securely. I pretty much need to stand guard if the oven is on when my son is around. Otherwise, he will try to stick his hand in to take things that are baking. B”H, he recoils from the heat so (bli ayin hara!) he has never been terribly burned. Please let me know if you have found any oven locks to be effective.

For the stove knobs, there are the standard safety covers that work until they don’t. I find it easier and safer to simply remove the knobs and to put them back on only when needed for cooking.

#### 3 Safety 1st Childproof Clear View Stove Knob Covers (\$8.97 for a 5 pack on Amazon)

### CABINETS

I remember the day we went swimming in cocoa, as my son was obsessed with both cocoa and water... Fun, fun!

If you have knobs or handles on your cabinets, there are lots of standard options you can find in the baby-proofing section of your local stores.

Alternate ones that have worked for us at different stages, as well as for various types of doors and knobs are:

#### 4 Multi-purpose Sliding cabinet locks (\$5.83 for a 6-pack on Amazon)

#### 5 Grip & Go locks (\$6.99 each on Best Buy) These are both standard and simple.

#### 6 Safety 1st Outsmart Flex locks (\$4.79 in Target) This one is pretty sophisticated and was more difficult for my son to master. I sometimes interlock a couple of them together to make it even harder to open.



Magnetic locks are another option. A magnet is attached to the inside of the cabinet, which locks the door upon closing. There is another magnet which works as the “key.” These can work in cabinets with or without knobs/handles.

There are two ways to install these, one with adhesive and one with bolts. The adhesive ones are very easy to install but they do fall off eventually. The magnets that screw in with bolts are, in my experience, unbreakable.

**7 Child Safety Magnetic Cabinet Locks** (No Tools Or Screws Needed) (\$24.99 for 20 Locks and 3 Keys on Amazon)

**8 Safety 1st Magnetic Locking System** (With screws) (\$22.81 for 1 Key and 8 Locks on Amazon)

For some reason, our keys would always get locked inside the cabinets! I remember one Erev Yom Tov when all the keys were locked in the cabinet. Lucky for us, our neighbor was a builder. He came with a super strong magnet and saved the day!

I suggest that you hide a few back-ups keys elsewhere. We stuck the extra magnet keys to the lights on our bathroom vanity.

B”H, I no longer need to lock my cabinets. Yehuda doesn’t spill things for fun anymore and now only takes what he really wants.

## THE SINK

Oh, how we love running water! It causes flooding, slipping and never mind the brand-new Shabbos outfit that now needs to be changed. A simple, but not very practical solution, is to turn off the water or lower the pressure. The knobs are found under the sink and they are super hard to turn. We have lowered the hot water temperature on the boiler to avoid burns.

A plumber recently told me about a special handle that can be put under the sink to replace the knobs. It needs to be professionally installed.

**9 Sharkbite ball valve** (\$12.28 on Amazon)

This requires just one turn to have it on or off. Please let me know if you have used this and whether it works well.

When we are in “flood mode,” I try using towels instead of shmattas to mop up. This makes my home look a bit nicer and feels more under control to me.

Of course, we try our best and Hashem does the rest! I look forward to hearing feedback and “Smart & Safe” ideas from all of our special families!





# Lets Get Educated

## ABA & Floortime™

There is a plethora of programs being used to help children with special needs, yet it can be challenging to get accurate information. In “Let’s Get Educated,” we present a very basic overview to help you figure out: “Is this for my child?”

ABA and Floortime™ are quite different approaches, but are often lumped together, since both are commonly used for children on the autism spectrum.

### ABA: Applied Behavioral Analysis

**When did it begin:** Dr. Ivar Lovaas is often credited with pioneering ABA therapy. It has been around since the 1960’s.

**Who are the target recipients:** While all children can gain from ABA, insurance only covers children who are autistic or “on the spectrum.”

**Where does it happen:** Evaluation and instruction generally takes place at home, in a daycare or school, or at a clinic. Instruction can be one-on-one or in small groups.

**How much:** The amount of therapy services varies on the child’s needs. Intensive ABA therapy indicates 25–40 hours a week for 1–3 years.

**What is the goal:** To help children who struggle with behavior problems, poor language and communication, and social skills.

**How it works:** Through observation as well as parental and teacher input, a therapist analyses the social and emotional behaviors that need support: specifically – the child’s behavior, how his/her behavior is affected by the environment, and how learning takes place. A plan of observable and measureable individualized goals is set up to increase the child’s functionality; by increasing positive behaviors and decreasing negative behaviors and/or to learn new skills and how to apply the skills. Each skill is broken down into small components and taught (adult directed) step by step to the child through reinforcement (and, at times, through consequences too).

**ABA in action:** 4 year old Chani is learning to dress independently. The ABA therapist creates picture cards to represent each article of clothing. Following along with the cards, Chani learns to put on each article of clothing. She is rewarded with tokens for each successful step, which accumulate to earn a prize.

### D.I.R. Floortime™

(Development Individual Differences Relationship)

**When did it begin:** D.I.R. Floortime™ (generally referred to as Floortime), was developed by Dr. Stanley Greenspan and his colleagues in the 1980’s.

**Who are the target recipients:** For children who are autistic or “on the spectrum.” It is not covered by insurance. However, Early Intervention providers and ABA therapists often can include the Floortime™ methods into their session. Out of pocket can cost \$40 –\$250 per session, depending on the expertise of the therapist.

**Where does it happen:** The child is usually evaluated at a clinic and a plan is set up. Instruction can take place at home, in school, or in a clinic.

**How much:** The amount of therapy services vary, based on the child’s needs. It can range from 6–8 sessions to years of service.

**What is the goal:** To help children who struggle with emotional skills and with relationships with the people around them. Sub-goals include: Broadening the child’s play skills with a bottom-up approach, and getting the child to participate and interact in a non-pressured way.

**How it works:** The Floortime™ method is an engaging, interactive approach, led by the child’s actions. The child and therapist will often be found on the floor with lots of toys. The therapist takes cues from the child and inserts direction in a subtle way.

**DIR in action:** Chaim, a six-year old boy with autism, likes to line up cars all the time and has little interest in anything else. The therapist will try to engage Chaim by adding a car to his line or maybe a truck. The therapist may put gas in the car or build a Lego gas station. Maybe she will create a street for the car to drive on, or simply jump with the car. A seasoned therapist will be focusing on the relationship the whole time. The therapist will try to get the child to participate without directly asking, but by strategically putting the car or themselves in a different spot. The therapist will also focus on extending the child’s interaction by sometimes doing silly things like putting the car in the child’s pocket, or making comments that encourage the child to respond.

# ***Flying A Kite Without A String***

By: Aviva Gross



I used to believe not long ago,  
 That to fly a kite one must hold on tight to the string and run!  
 Run with the wind on my back, the gust hurrying my feet,  
 As I watched my kite soar to the heavens.  
 And if I felt a tug,  
 I would let out more string.  
 But never let go of that string!  
 Never let go, hold on for dear life!  
 The string was all I had,  
 All that was left up to me.  
 I have now discovered a new and improved method for flying a kite.  
 One that takes away the problematic aspects of traditional kite flying;  
 Like getting your string caught in the branches of a tree,  
 Or hopelessly tangled,  
 Or pulling too hard at the wrong time , causing your kite to take a sudden swoop and loose it's buoyancy.  
 It's called; "Flying a Kite Without a String."  
 No more string!  
 Goodbye!  
 For it was really never up to me.  
 I will now watch with my feet firmly planted on the ground.  
 Step by step and day by day,  
 I will follow  
 To do your will Hashem.  
 As You will take me  
 Just where You want me,  
 When and if and how.  
 Not mine to control.  
 Never was and isn't now.

# A Tightrope

By: Leah Tawil

I'm walking a tightrope.  
 Carefully,  
     Delicately,  
         One foot in front of the other.  
 Careful not to tip,  
         slip,  
             trip.  
 Not too much on one side              but not too much on the other.  
 Keeping the delicate balance.  
 That delicate balance,  
     Just the right amount -      on each side.  
     Bitachon                      -      Hishtadlus  
     Hashem's in control -      I do my part  
     Only Him                      -      My very best.  
     It's so hard                      -      to keep that balance.  
     How do I know?              -      How much to try?  
     When is it time?              -      To move on?  
 One foot in front of the other.  
 Some days it just doesn't seem fair.  
 I feel as if things are unbalanced  
 I just can't seem to get it,  
 To find that  
     delicate balance.  
 I keep moving,  
 One foot in front of the other.  
 When the world is swaying beneath my feet,  
 When the rope seems to shake and quiver,  
     First one way                      -      and then the other.  
 I put a smile on my face,  
     And keep going  
         One foot in front of the other.  
 They don't know  
     The audience doesn't see,  
         What's happening inside.  
     It looks easy:                      One foot in front of the other.  
     It seems effortless:              Keeping that delicate balance.  
 They only see from below,  
     He who sees from above – He knows.  
 I will keep moving,  
     One foot in front of the other.  
         Keeping the delicate balance.





Dear Readers,

We hope you enjoyed our first issue of Neshamale magazine, that you gained from it and that it gave you chizuk.

We would love you to contribute your own perspectives, tips, poems, stories -anything you would like to share. In order for Neshamale to really take off, we need you to be involved and make this 'our' magazine, a forum for Special Needs families to share.

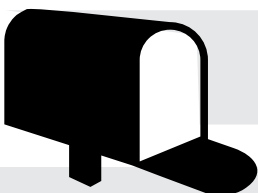
Years ago I heard a man say something that made a huge impression on me and I have not forgotten it to this day. He started his speech with the words, "Thank you for coming here to listen to my story. Every time I speak, I feel myself heal a bit more." Every time we share our stories or the thoughts and feelings that accompany them, we heal a little more, accept a little more. We hope that sharing your never-ending magnificent journey will help you, as it will surely help others!

If, among our readers, there are those for whom this magazine caused even more feelings of isolation (who may feel that even the Special Needs community doesn't "get" you), we feel for you and daven that you find appropriate resources to help you feel supported. Perhaps you can share with us what you are dealing with and link up with others in a similar situation.

Finally, please involve your "other" children, the "Special Siblings," who are so strong and blessed to be growing in this way. They need support as much as you do! Please encourage them to read the "Sibs Spot" section and to send in their own stories, questions, etc.

We look forward to hearing from you!

Neshamale Staff



## INBOX

I read your letter in The Voice of Lakewood and I am interested in hearing more about your idea. What is your goal with this magazine? Who is your target audience? Can you share some more details with me?  
Sarala S

Dear Sarala S,

Hi and thank you for your interest. I will try to answer your questions. The main goal is to create a sort of support group in the privacy of our homes. Live support groups are phenomenal if they work for you. For a variety of practical and emotional reasons, they don't work for everyone. This is a good "second best" or "in addition". We all have feelings, ideas, advice, questions... and many don't have who to connect with. We are encouraging a lot of reader input for the benefit of everyone reading it. If you have any topics that you would want to see covered, please send me your ideas. Also, we have connections with Rabbanim, doctors, therapists, etc. and can forward your questions to the most appropriate party to answer.

It is meant only for the families of special needs children so it is not a "public" magazine but obviously it is not "private" either. As far as the target audience, it is not my place to decide which children are considered "special needs" and which aren't. I am leaving it open to any family who feels they can benefit from reading the magazine.

*I feel that even if nothing in a particular issue applies to someone reading it, they will still gain a lot by feeling part of a group of amazing people who are doing the same thing as them, struggling and triumphing in similar ways that other people in our lives have a hard time understanding. Just knowing we are not alone is encouraging. Hope that clarified it a bit more,*  
Chayala

It's Esty here, regarding the article I promised you: I wrote it up and shared it with my family to get their opinion. Don't know if that was a good idea. My teenagers are mortified and forbid me to print it.

Hi, Esty!

I'm so excited to hear that you wrote the article. Here is a simple solution to your teenager's worries: you can use a pen name and change some minor details like your city, etc.. Of course we are not ashamed of our special neshamale's but sometimes we do need to protect our family's privacy. A pen name is perfectly fine. Let me know if that works for you.

Chayala

My name is Mindy and I live in Monsey. I heard about the magazine that you are

starting and I am very excited about it. There is a real need for something like this. I'd love to share my story but I am not a writer at all. Not sure how to go about that. Let me know how else I can be of assistance,  
Thanks, Mindy G

Dear Mindy,

Thank you for your interest! As far as writing goes, none of us are really professional writers! Writing from the heart is a beautiful language in it of itself. We do have an editor who will polish each article as well. Another option is for you to tell your story or share your thoughts through an interview format. The interviewer (from our staff) would be the one to write up your responses. Let me know if any of these ideas appeal to you. I'm sure everyone would gain from hearing about your experiences.

Be in touch,  
Chayala

How do I sign up for the magazine? How much does it cost?

Welcome to Neshamale Magazine! There is no cost. We do welcome donations and sponsorships. Hope you will enjoy!



“ I thought I would have to  
teach my child about the world.

Turns out I have to teach the  
world about my child. ”