

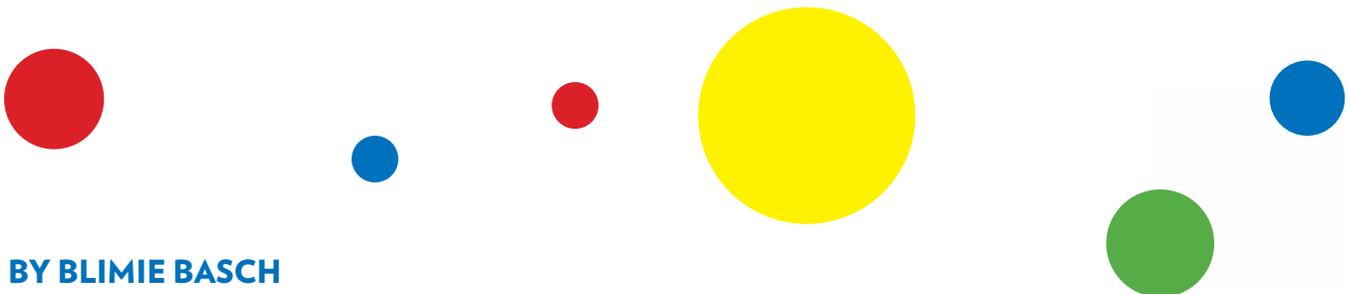


A NEW
SCHOOL

OF THOUGHT

*Championing the education of
immunosuppressed children*





BY BLIMIE BASCH

For most people, exposure to the harsh reality of childhood illnesses like cancer, heart defects or respiratory deficiencies has been through the growing number of magazine articles, media reports and public relations initiatives. Lengthy hospital stays, painful procedures and side effects have all been painted in vivid detail in these accounts. Yet words and audiovisual clips — no matter how moving and true to life — can never accurately portray the challenges these families endure.

Nausea, weakness, hair loss and mood swings are all physical changes that are easily recognized by most, even those unfamiliar with any patients. But the hidden dimension and side effect that has not been brought to the fore is the issue of immunosuppression in children and the educational experiences, or lack thereof, that they suffer. For most of these children, even while released from medical facilities, their immune systems are too compromised to allow them to attend school with their peers, sometimes for up to two years. The long-term effects, cognitively, emotionally and behaviorally, on them and on their families' dynamics can be very difficult to cope with. One organization in Brooklyn set out to create a solution, and in doing so created the only place of its kind for immunosuppressed children. Meet the Kapayim Center.



This one-of-its kind pre-school provides pediatric patients with a regular educational experience



NO CHILD LEFT BEHIND

It's Nachman's first day back in class after an extended leave of absence due to a hospital stay, and he's the center of attention. For about five minutes. Then it's business as usual; time for hand washing, then *davening*, singing songs, daily exercises and learning.

The breakthrough comes at lunchtime. Due to his loss of appetite, Nachman has refused to ingest even a morsel. His doctors, nurses, parents and the hospital's child-life specialists have begged and pleaded with him using every tool and method at their disposal, to no avail. Nachman kept his lips tightly shut and was therefore hooked up to a TPN (total parenteral nutrition) to meet his daily nutrition needs.

When he sat down at the table with his classmates and observed them eating lunch, he wolfed down an egg, a full serving of protein, to his teachers' amazement. His parents celebrated on the phone when they received the call from the delighted teachers.

Penina arrived from Eretz Yisrael with a serious medical diagnosis, and a troubling emotional report. Her inability to interact with others, her frequent outbursts and tantrums alternating with long periods of silence and withdrawal, troubled the doctors in charge of her care.

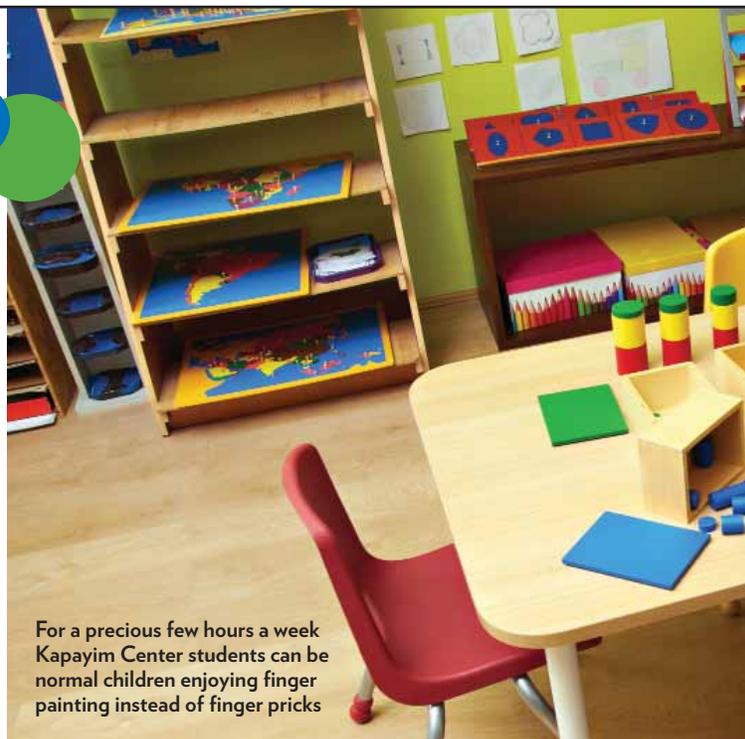
But as they prepared to spend weeks in America while Penina received treatment, her parents worried that her behavioral challenges would be too difficult during this time with little to no structure and lots of pain and medical intervention, and all this in a foreign country with a different language.

Her despairing mother brought her to the Kapayim Center very reluctantly, with not much hope of her adapting. Upon entering the room, however, Mrs. Esti Halberstam, the teacher in the class, just lifted the child up and held her close as the mother slipped away.

And today, a month later, Penina is a calm and expressive child who excitedly looks forward to attending the class on her days off from treatment. When her teachers come to visit her in the hospital with the arts and crafts, weekly newsletter and curriculum activities she missed in class, she cannot contain her excitement. There are no tantrums or brooding silences, for Penina's anxieties were alleviated by the stability of her classroom routine and new little friends. And her oncologists look on in disbelief at the complete transformation of this precious child.

"We provide the medicine," shared Dr. Sharon Gardner, pediatric oncologist in NYU. "but it's your people and your work who provide the cure."

Mrs. R. arrived at the Kapayim Center straight from her son's weekly radiation treatment at Memorial Sloan Kettering Cancer Center. "Just take him," she said. "It's been a really hectic morning. We've been out since 6 a.m., and I need to put my house together and run a million errands, so please keep



For a precious few hours a week Kapayim Center students can be normal children enjoying finger painting instead of finger pricks

him here for whatever's left of the day."

"When a mother says something like that to you," says Ruchelle Haas, another teacher at this preschool that is the only one of its kind, "you remember that it's not just the children you're helping daily; it's the whole family unit."

Where are the bald heads and listless patients associated with illness?

In the Kapayim Center it's learning as usual in a sterile classroom that appears typical of a preschool. *Alef-beis* and cheerful learning posters are tacked to the sterile walls alongside *mitzvah* notes and smiley stickers. Diminutive chairs and tables, smocks and paintbrushes, books and toys are all organized throughout the room. Nourishing meals, snacks and drinks are served, with the addition of lots of hand washing and "Purelling," three devoted teachers, and a nurse and two doctors on call for any questions or concerns that may arise.

These children share a special bond. They are no strangers to illness. And while their everyday lingo includes ports and pricks, IV drips and transfusions, for a precious few hours a week they can be normal children enjoying finger painting instead of finger pricks and learning about the *parashah* instead of watching DVDs all day to distract them from their treatments. These children delight in the normalcy and stability of learning like everybody else.

"Our goal is to try to keep them on a par with other children their age, in all areas. We do all kinds of physical activities with them so that they can build up their strength, encourage healthy eating habits, and of course concentrate on learning that builds their cognitive skills," says Ruchelle Steiff, the assistant teacher.

The most heartwarming, though, is the bond these children share. Going to hospitals and undergoing procedures is all routine in their daily lives, and they are very understanding



ACADEMIC CHALLENGES FACING SURVIVORS OF CHILDHOOD ILLNESS

With the great advancements in medicine, *b'chasdei Shamayim*, more and more children are surviving pediatric illnesses. However, in children the hidden side effects of childhood illness are proving to be the most crushing ones. The formative years of childhood are when the child develops socially, emotionally, academically and behaviorally. A child who is a patient in his or her early years loses out on a great deal of this fundamental development.

According to the American Cancer Society, the average duration of chemotherapy, radiation and cancer treatment is two years. The average number of school years missed by pediatric cancer patients is two grades. In addition, studies have shown that one-third of cancer patients have marked academic difficulties post-treatment due in part to having lost out on time in school.

Additionally, for the average two years that these children are enduring treatment, much of the time is spent at home. The fact that they are in pain or discomfort, have not had structure during their formative years, and are not stimulated enough academically can cause significant behavioral challenges in the home, affecting the family dynamics as well as inhibiting the parents' ability to work or function normally.

ESTABLISHING THE KAPAYIM CLASS

Until two years ago, there was only one preschool on the East Coast for the immunocompromised child, the Morgan Center in Long Island, a preschool for children with cancer. It was only after seeing the real need firsthand for so long that the directors of Kapayim sought to establish the first *frum* preschool for immune-compromised children suffering from pediatric illnesses. After nearly two years of operation, its success speaks for itself.

Kapayim is an organization that was founded to assist families of those suffering from illness. With a vast network of hundreds of volunteers, they have been providing much-needed relief in homes and hospitals to all members of a patient's family on a daily basis. For the hundreds of families they have assisted, Kapayim has been a household name they utter with gratitude and relief. The organization's priority is to operate with discretion and complete respect to patients' privacy.

and compassionate when a classmate is going through it.

"One day, one of the kids walked in and said to me, 'Yesterday, I went home and I cried because my friend E. is not here,'" relates Esti Halberstam. "It's amazing that the children have each other. When a child is absent, they worry about each other to an extreme, they understand what their friend must be going through, and the pain they feel for each other is real. These children don't need to be told; they understand instinctively."

"It definitely has its challenges, though," says Devorah Friedman, the nurse in the classroom. "The children have very different needs. For example, a child who is a heart transplant patient can be very weak, need, lots of physical therapy, and need help with regular activities, whereas the cancer patient on steroid treatment can be so full of energy that he is hard to control, and we need to gear our activities to both at the same time."

"But we do; and just watching the children in action, with glowing smiles and unsuppressed excitement each and every day, is worth all our efforts of maintaining a sterile environment with a regular preschool schedule," Esti states with pride.

"But hygiene is something that has already been ingrained in the children, and they are just as cautious as we are," explains Ruchelle Steif. "First thing in the morning when the kids come in, they know to do a rub-a-dub, smearing Purell into their hands, and it's an activity that's repeated many times throughout the day. They also wash their hands with soap and water before they eat, and after using the bathroom, and know not to touch each other's food, or stuff. The parents and children know that the first sign of illness means they have to inform us and keep the child home so that we can take the necessary precautions in the class."

Because it was founded by educators, Kapayim’s goal has always been to engage the patients, siblings of patients and children of patients with constructive activities in which the children are not only entertained and kept busy, but at which they can learn, play and create as well.

These inspirational women have been involved with servicing *cholei Yisrael* in the community for over a decade, supervising a cadre of volunteers who do whatever is needed to maintain family stability in the home, whether it is helping with siblings’ homework, covering hospital shifts or tutoring patients. These women, who also have growing families of their own and distinguished positions in *chinuch*, realized there was an urgent need for a multipurpose center, a center that would serve both the patients and their families. Patients who are immunocompromised can come during the days when they are not being treated, and siblings or children of patients can come after school hours to do homework, play stimulating games, and have interesting activities and fun.

“I believe that children deserve to be children,” says Mrs. Pessy Klagsbrun, one of Kapayim’s founders, who is also a preschool director. “I met one mother with her three-year-old daughter who had recently been diagnosed with cancer. The child was sitting in a wheelchair, covered with blankets, her eyes barely peeking out. ‘This is how it’s been since she started treatment,’ the mother offered by way of explanation. ‘But it doesn’t have to be!’ I explained to her.

“We slowly trained the child to interact normally and have healthy social skills. First volunteers read her books, then they played interactive games with her, and the child actually began to live again. Today she attends the Kapayim class on her days off from treatment. She is an adorable, happy student. The belief that these children deserve to be normal is life-altering.”

This little girl’s nine-month regimen of treatment was reduced by three months, and her doctor attributes the success of the medical protocol to the learning this child did throughout.

“In high school, I volunteered to visit cancer patients who were homebound,” recalls Mrs. Yitty Fisch, a high school principal and a founder of Kapayim. “It was Erev Pesach and I was asked to watch Dina’le so her mother could shop for Yom Tov. When I arrived, her mother said, ‘Do me a favor; she had enough of the coloring. Could you teach her something about Pesach?’ I asked her to wait a few minutes and I ran to Eichler’s, where I bought a book on Pesach.

“We went through it page by page and she soaked it up like a sponge. We created an arts and crafts *Haggadah*, just like they make in school. We practiced the songs and the *Mah Nishtanah*. Dina’le passed away that Tishah B’Av, but her mother couldn’t stop thanking me for that Pesach, when she stood up at the *Seder* and was able to recite it all amidst her parents’ tears of pride and joy.”

It was that encounter with Dina’le that inspired Yitty, not only to ensure that making a difference in the lives of ill



children and families would be a large part her life, but also that all the children would be cognitively stimulated, particularly so they would not lose out on their Judaic education.

The Kapayim Cabin was created, first in Williamsburg and more recently in Boro Park, to offer a place for siblings of the ill to learn, play and recharge. It is a learning and recreational center, where children whose lives have been disrupted by illness can enjoy stimulating, educational learning in a fun-loving atmosphere.

The center has become a safe haven and second home for children whose parent or sibling is hospitalized. When biopsies, procedures and doctors’ appointments stretch past school dismissal time, children who come straight off their buses are warmly greeted by designated “cabineers” at the center. The Kapayim members, with whom they are already familiar, will ask about their day, serve them a warm meal, and get them started on homework. Afterward they will work on their *parashah* or Yom Tov project of the week. The thematic educational activities change weekly, so that children anticipate coming to the Cabin.

With the success of the Kapayim Cabin, the founders’ dream of establishing a *frum*, sterile classroom was also realized two years ago. Now the Kapayim Center houses the preschool during the day and the Cabin during after-school hours.

There are cozy nooks, bean bag chairs to sit in to read, closets of books and workbooks, games, and toys. There is a set of *Chumashim* in the bookcase. It’s Faigy’s when she needs



Kapayim's goal is to engage patients, siblings and children of patients with constructive activities

to do her *parashah* homework, Leiby's when he is *maavir sedrah* with his *chavrusa*, and Simcha's when he reviews his *kriah*.

"There was an elementary school-aged child whose mother was only worried that her daughter was going to have to be left back and repeat the grade she was in when she finished treatment," says Mrs. Yachy Schweid, another one of the founders. "And as the principal in a girls' school, I understood her need to fit in with her peers.

"We provided her with enough private schooling and one-on-one teachers that she was able to keep up with her classmates throughout her ordeal. The child transitioned from treatment right into her seat in her own classroom. It meant so much to the mother, to the child and to us."

At Kapayim, stimulating their minds is not used as a means of distraction; it's a means of healing.

"KIDS NEEDS TO BE KIDS"

Eli, a 2½-year-old boy who had been in the hospital on treatment for most of his young life, kept insisting that he wanted to go to *cheder*. His mother lovingly assured him that when he was big and had a *yarmulke* and *tzitzis*, he would go to *cheder*. She knew, though, that exposing Eli to the germs of a typical classroom could be extremely hazardous to his health. His *upsherin* was a quiet, emotional affair. Following his radiation treatment that morning, there was no hair to cut, but his mother, determined to deliver on her promise, made arrangements to bring him to Kapayim's sterile class. Eli was smiling from ear to ear as he enjoyed his moment in the limelight of a regular classroom. And when he was stable enough, he became one of the students in the class.

"Kids need to learn; kids need education; kids need structure, and most importantly, kids need to be kids —

especially children that are going through trauma," is a sentiment all three founders reiterate.

"My daughter had a heart transplant, and if you ask me how I coped, it was only thanks to Kapayim's support and their preschool," says Mrs. G. "My daughter's social life and preschool skills were given the opportunity to grow. The immunosuppressed kids fall so far behind, they really need school. On the days she doesn't go to school, she stands at the window and waits. This is a necessity!"

Therapists routinely visit the classroom to provide their clients with speech, physical or occupational therapies. Two therapists were overheard conversing in the hallway of the Center. "Can you believe this is the same kid we saw last week in the hospital?" one asked. "The progress is remarkable!"

"Of course it is," answered the other. "It's this place, this classroom, that gives them the boost and strength to push themselves. Here we see the greatest developmental progress," she exclaimed.

"Our *nachas* is having our graduates mainstreamed into regular classrooms and being told by their current teachers how they would never be able to tell what these children went through because they are coming from a regular setting, doing what regular preschool children do," says Mrs. Halberstam.

As one mother so emotionally expressed, "When my husband reviewed the *alef-beis* Shabbos afternoon with my son, and he knew it so well, the hope in me blossomed and burst forth. Yes, Chaim Tzvi will *im yirtzeh Hashem* get well, and he will be able to learn, and be on a par with other children his age. Dare I believe that next year he'll be in a regular *cheder*?"

The Kapayim Center will do everything it can to ensure that Chaim Tzvi and his peers be mainstreamed into regular classrooms when they receive their clean bill of health. ■

1. Purell is an instant hand-sanitizing lotion.