



Keren Malki: A Letter to Our Friends

An Update from the Malki Foundation, Jerusalem ■ June 2007

Report from Jerusalem: An Update on Activities

“Your assistance is helping us tremendously, inspires us with optimism and gives us strength and hope for the future” write the grateful parents of a 3-year-old child diagnosed with autism in a recent “thank you” letter to Keren Malki. “We know that with the right help given intensively to Nadav we can give him a fair chance for his future.”

Keren Malki, established in 2001 to memorialize the life of Malka Chana Roth, continues the precious work she started. More than 1,100 disabled children and their families have already been helped by the foundation. Through two successful programs, we fulfill needs not met by any other organization.

Keren Malki’s *Therapies in the Home National Program* began its work in 2003, aiming to empower families who are raising a disabled child at home by providing them with the means to impart the best possible care. This, as you can imagine, impacts our many families in very different ways.

To some, the availability of intensive treatment means their child will be enabled to walk; to others, that their non-verbal child will learn to utter “Mummy” or “Daddy” for the first time.

The work of Keren Malki lets families from every part of the Israeli demographic spectrum make their own decisions about the therapies that are best suited for their

child. Thanks to the generous assistance and support of people from all over the world, **we’re proud to announce that we have recently hit a major milestone – 15,000 therapies** as of May 1st 2007! Speech therapy, occupational therapy, physiotherapy, hydro-therapy and

therapeutic horse-riding – delivered fifteen thousand times as of last month. That’s a considerable amount of progress for a lot of children.

Our second project, the *Keren Malki Unit at Yad Sarah*, is a joint venture with Israel’s best-known (and the world’s largest) equipment-lending organization, providing therapeutic and rehabilitative equipment for home-cared children on a loan basis, free of charge, to anyone who asks for it. Equipment loans are typically made for a year, but longer under certain circumstances.



Keren Malki’s busy equipment warehouse and demonstration center at Jerusalem’s Yad Sarah Center

The Keren Malki Unit opened its doors in January 2003. What makes this partnership especially great is that Yad Sarah continues to do what it does best - lend out equipment on a free-of-charge basis, while Keren Malki continues to do what it does best – helping to meet the needs of families caring for a child with disabilities within the family home.

The Keren Malki Unit provides hospital-beds, standers, walkers, bath-inserts, hoists and a host of other items for such families. Hundreds of such loans have been made to Israeli families from every walk of life and from every part of the country. They go a considerable way towards helping such families give their child what they – the parents, the family – feel is the best possible care. ■

A Family's Experience*

TWENTY SIX WEEKS INTO MY PREGNANCY, the gynecologist noticed a problem. "You seem to have too much amniotic fluid, but don't worry, most women who have this problem continue to have very normal pregnancies."

Unfortunately, I guess I wasn't most women, as a week later I went into spontaneous labor which landed me an emergency cesarean section. Nathaniel, my newborn with the excess amniotic fluid, came out blue and needed emergency resuscitation. At first the doctors did not believe that he would live. His lungs were so bad that it was almost impossible to ventilate him. A very long week later, some optimism crept into their voices, and words such as "might possibly survive" entered their lexicons.

As weeks turned into months, ventilation began to be easier and Nathaniel began to breathe on his own. However, with the realization that he would survive, there were new hurdles to overcome. Nathaniel had a serious brain bleed, meaning that his neurological outcome was unclear. Would he be blind, would he be retarded, would he have cerebral palsy, or would he be a vegetable? At one point, the social worker hinted at "homes" that we could leave Nathaniel in. I was irate and stormed out of the meeting; she could put her own children in such places, mine was coming home with me.

The year passed with trepidation. Whereas cognitively he was developing nicely, smiling and even starting to talk, his physical condition indeed seemed bleak in spite of physical therapy. Doctor after doctor gave the diagnosis of cerebral palsy, which - though we expected - still dreaded. It seemed his cerebral palsy would be severe. We took him to a rehabilitation specialist who explained to me the grading score for judging the severity of CP. According to what Nathaniel could do at age one, he could predict what he would do at age 6, at age 13 and even as an adult. According to the charts, since Nathaniel wasn't able to sit independently, he would be wheelchair bound for the rest of his life. He recommended buying a motorized wheelchair

early on. My husband was irked by the doctor and his predictions.

"Let's prove him wrong," he told me. I was less optimistic and was already getting estimates on the chair. The doctor was quoting articles from major medical journals; who were we to argue with the best neurologists in the world? My husband, however, was insistent. "Let's increase physical therapy; if after a year of extreme intensive physical therapy, he doesn't improve, then we can buy his wheelchair."

I relented though I was convinced my husband was unrealistic. We began to do physical therapy 3-4 times a week. We added water therapy. Once a week, we began occupational therapy to improve the function of his left arm. We also started speech therapy to try to avoid the speech impediments cerebral palsy patients often have.

We began to see improvement. A month after we went to



Nathaniel at Purim

the rehabilitation doctor, Nathaniel began to sit independently. A few months later, he began to crawl. It was a funny crawl that resembled a bunny hop, but it nonetheless qualified as a crawl. It gave

us endless satisfaction to see the doctors looking at him, scratching their heads and saying "Gee, I didn't believe he would be able to do that." He began to walk with a walker, one step, two steps. It was a great day in my life when Nathaniel "walked" ten steps with a walker (with me holding him from behind and the physical therapist holding from the front but who was counting?)

* The anonymous writer, the mother of a young child with special needs, resides with her husband and children in the Tel-Aviv area.

Whereas all these treatments were paying off in terms of improvement, they were decimating us financially. The amount of therapies Nethaniel was having was costing us three thousand shekels each week. My husband and I both have good jobs but we were having a hard time producing this type of money.

Both of us increased our working hours, but it wasn't enough. I would spend night after sleepless night worrying how we are going to pay next week's physical therapy bills. We began to debate stopping the treatments because we just could not shoulder the financial burden any longer.

I can't remember how I heard about Keren Malki but do remember writing an e-mail to Mrs. Roth asking for help. I didn't expect much since other organizations I had turned to before were so cold and unfriendly. When Frimet called, I was overtaken by her compassion. She actually listened and encouraged instead of telling me to fill out fifteen forms in triplicate. My husband, however, was skeptical. He was convinced that it was too good to be true. He thought that there must be a catch somewhere... until we got the first check, which paid for 75% of the previous month's therapies and we didn't have to take another mortgage on our apartment... and we didn't have to sell our car... and we could afford to increase the number of treatments Nethaniel received.

Nethaniel is almost three now. He speaks two languages and can count to ten in English and Hebrew. He walks with his walker everywhere. He walks to synagogue on the Sabbath and to the playground during the week. He is starting to use tripods, which are two cane-like sticks which one uses after graduating from a walker. Our physical therapist says that there is a good chance he will walk independently some day.

Somewhere in a remote warehouse, there is a motorized wheel-chair that my son will NOT be using. Thank you, Keren Malki! ■

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Honoring Those Who Make Our Activities Possible

Foundations Our sincere thanks are expressed to the trustees of several foundations and institutions for their generous support in the past year: **The Abeles Liberman Trust, Bachrach Charitable Trust, The Harry and Jeanette Weinberg Foundation (Baltimore), Intract Charitable Trust, Kol Chai Hatch End Jewish Community, Mermelstein Family Foundation, Joshua and Sherie Miller Family Fund, Neve Orot Synagogue Jerusalem, the Simon Giving Fund, Students Against Terrorism, Young Israel of Riverdale NY.**

Family Milestones Our sincere thanks and congratulations to families who chose to associate their personal family celebrations with our work by asking their guests to contribute to Keren Malki in lieu of personal gifts. In particular: to **Marcy and Adam Cohen** of Englewood, New Jersey – on the birth of Caleb Benjamin Cohen; to **Menachem and Merav Yisrael** of Jerusalem – in honor of Dora and David Yisrael's 50th Wedding Anniversary; to **Eliat Weizman** of South Caulfield, Australia - in honor of her Bat Mitzvah; to the family of **Ruth Feiglin** of Kiryat Ono, Israel - in honor of her special birthday; and to **Bill Nelson** of the Embassy of Australia in Tel-Aviv – who came in second in the Footy Tips competition. ■

Keren Malki's Executive Director Writes: Meeting Unmet Needs

Liat Behr

“FOR MANY FAMILIES, THE DECISION to raise a special child at home is often fraught with agony. Life is consumed by a daily struggle to accomplish that which for others is routine. It takes time, energy and spirit to raise a healthy child, but the special-needs child impacts these realities in ways not easily imagined by others. Developmental disabilities affect far more than the person born with limitations; anyone who lives with, cares for or cares about a disabled person is keenly aware of the pronounced social and emotional attitudes of the surrounding society... A family without comparable support will suffer burnout.”

[SOURCE: The Jerusalem Post – reprinted by permission.]

As if the challenges facing a family raising a severely disabled child weren't enough, such families often find themselves facing bureaucratic agencies that encourage them to institutionalize their child. Families who choose to care for their child at home will often bear the brunt themselves, receiving either very little or no assistance from the government.

According to a study sponsored by the National Insurance Institute (NII), the Joint Distribution Committee, and the Brookdale Institute in Jerusalem, only 12% of special-needs children receive a National Insurance Institute (NII) stipend because of strict eligibility conditions and approximately one-fourth live in households in which neither parent is working. Only 40% receive the medical treatments and follow-up they need and only 33% of disabled children will receive the para-medical treatments recommended by doctors.

These alarming figures stress the dire need of disabled children in Israel. The fact that only one-third of those requiring para-medical therapies receive them means that two-thirds are *not* receiving these therapies and will therefore not be able to develop to their full potential.

The work of Keren Malki is about empowerment. It is about giving parents the ability to decide what is best for their child – the parent determines what type of therapy may benefit their child and who the best therapist to give it is. Keren Malki is about fulfilling needs and making a difference, enabling parents to give their child no less than the best possible care. ■

Meet Our Board Members

DR. JOEL (JERRY) LAFAIR, a pulmonary medical



specialist, is presently in private practice and a consultant in pulmonary medicine at Herzog Hospital in Jerusalem. Originally from Philadelphia, he and his family made *aliyah* to Israel in

1971, settling in Jerusalem. Dr. Lafair is one of the seven founding members of Keren Malki and an active board member.

How did you become involved with Keren Malki?

My involvement with Keren Malki, started on that beautiful August day when we heard that Malki and her good friend Michal Raziel had gone to town together and were missing following the terrorist bombing of the Sbarro restaurant in the center of Jerusalem. Both of these girls were neighbors of ours and their parents our good friends. First there was a report that Michal was in the Shaarei Zedek Hospital and was being operated on. However, unfortunately it was soon confirmed that she was among the unfortunate victims of this murderous act of a Palestinian terrorist.

The Roth family was devastated by this news, since they knew that the two girls would have been together, however there was no news of anyone answering Malki Roth's description when we checked at all the local hospitals. At a late hour, Malki's two eldest brothers were sent to the Abu Kabir forensic medicine center in the outskirts of Tel Aviv to identify her among those victims who were blown apart. After midnight, we were with Arnold and Frimet and their other children when the fateful call confirming her death was received.

During the *shiva* (the traditional mourning period of seven days) when Arnold and Frimet decided to initiate the Keren Malki fund to assist all deserving children suffering from a variety of disabilities to continue to live at home, I was happy to become a member of the board and help in whatever way possible.

Has your occupation provided you with any insight into the work of Keren Malki?

Being a physician involved in pulmonary medicine for the past forty years allows me to know of the tremendous assistance which Keren Malki gives to the families of children that would have been placed in institutions in the past. The necessary appliances, special beds, chairs, braces and so on, which allow for the child to remain at

home have been bought by Keren Malki and distributed through Yad Sarah. It also provides for necessary home treatments by physiotherapists and other health workers, which the health funds do not provide. ■

Students Against Terrorism Raise \$31,000

By Daniel Bonner*

GENERALLY, COMMUNITY ACTIVISM in support of Israel in the United States and beyond is led by adults, with students serving as “behind the scenes” volunteers. Students Against Terrorism subverts that notion, placing students at the forefront of fund-raising and awareness activities in the Dallas, Texas Jewish community. SAT, as our organization is known, was founded in 2002; our first event, held at Shaare Tefilla, a modern orthodox synagogue in Dallas, raised about \$5,000. The students involved recognized that with a united, collective effort, a great deal could be accomplished.

We can ease the pain of the many affected by suicide bombings and other daily attacks. Our organization grew from just a few members to include nearly every student in our school, Yavneh Academy, and hundreds of community members lending financial support and spending time advising and supporting our efforts.

We first learned about Malki Roth, z”l, watching CNN’s *Impact of Terror* presentation, which shared the experiences of those affected by the *pigua* at Sbarro in August 2001. We were moved by Malki’s story – her commitment to *chesed*, her dedication to family – but most poignant, for us, were the actions of Malki’s parents and extended family in the wake of the tragedy. If they could transform tragedy into hope, we understood that it was our responsibility to help Arnold and Frimet



Roth and the many families for whom they provide aid, in any way possible.

After hearing from Mr. Roth and learning about their past and future goals, the student leadership of SAT was united, deciding to send the proceeds of our fourth annual Points for Peace basketball tournament to Keren Malki. On March 5, 2006, at the Jewish Community Center, 300 players (which constituted about 70 teams), 100 volunteers, and hundreds of spectators came together to participate in a day-long 3-on-3 basketball tournament. We raised \$30,000 to contribute to Keren Malki’s therapy programs, participating in Tikkun Olam and uniting the Dallas Jewish community behind the hope of peace in Israel.

A school in Florida learned of our efforts at the Eimatai Leadership Development Conference, organized by Yeshiva University’s Center for the Jewish Future and on Lag Ba’Omer 5766, the students at Rabbi Alexander S. Gross Hebrew Academy organized their own Points for Peace

basketball tournament, adding \$1,000 to our grand total, helping SAT surpass its fund-raising goal.

In a letter of thanks to the Dallas Jewish Community, Arnold Roth wrote the following: “We have our powerful Jewish traditions and Halacha to inspire our next steps. Those are the inspiration for the work of Keren Malki. We will take your Points for Peace money and spend it wisely and effectively, helping to remind people

about the enduring values of Jewish society, and about the life of one fifteen year-old girl.”

Students Against Terrorism, through fund-raising and other efforts, hopes to continue to bring alive that tradition, helping Keren Malki and the many other organizations that do similar work. Thank you for standing with us as we seek to build a bridge between our community and the people of Israel. ■

* Daniel, aged 16, a high school student from Dallas, Texas, is Executive Vice President of Students Against Terrorism

When You Think of Her

AFTER THE LOSS OF THEIR DAUGHTER, A FAMILY SETS UP A FUND TO ASSIST SPECIAL CHILDREN

*By Michele Chabin in Jerusalem**

WHEN MALKA ROTH, a popular, vivacious 15-year old, was murdered in the August '01 Palestinian terror bombing of the Sbarro pizzeria in Jerusalem, her inconsolable family searched for a way to honor her memory and share her spirit. By the time they had gotten up from *shiva*, the Roths had decided to establish a fund to help families care for their severely ill or special-needs children at home.

"It was the perfect fit for a girl who was so sensitive to special-needs children. She was amazing," says her mother, Frimet, whose lingering pain still prevents her from uttering the words "Malki Foundation."

Malki's bond with special children evolved at an early age, her mother says, because Malki's sister, Chaya, is blind, severely epileptic and profoundly mentally disabled. "She really loved Chaya, and Chaya was drawn to her in a special way," Frimet says. "She knew how to feed Chaya when no one else could, and I relied on her. Perhaps more than I should have."

When Malki volunteered to help a neighborhood toddler with Canavan's, a fatal Jewish genetic disease in which the child's mind and body waste away, "she picked up the small things" in the boy's expressions, "even though his reactions were so minimal," Frimet says. At school, Malki gravitated toward the group of learning disabled girls in a parallel class; just two weeks before her death, she volunteered at a camp for special-needs children.

"This was the right charity," Frimet says quietly. Drawing on their own often-futile experiences with Israel's national health care system, the Roths decided to provide the kinds of services the health funds (like HMO's) do not. "We were already sensitive to the needs of disabled children," Arnold Roth, Malki's father, says. "We'd been in battles with the medical establishment over the simple right to

keep our child at home rather than institutionalize her. We utterly refuse to contemplate the idea of institutionalizing Chaya because no one can give a child the kind of care that a family can."

When the Roths sought the equipment and therapies they would need to provide Chaya's round-the-clock care at home, they found the system "would not listen to people like us. We knew that other families were in the same situation. It's heartbreaking to see how the system is failing the special-needs children of this country."

The Malki Foundation, which relies totally on donations, pitches in after parents have exhausted all other options.



In her last week of life, Malki was a counselor at Etgarim's summer camp for children with special needs

Although the health funds do provide physical therapy, for example, "the amount allotted falls far short of what a severely special-needs child needs," Arnold says. "Generally, treatments are measured in terms of the total visits to a therapist per year, and that number rarely exceeds 20."

Every day, parents of special-needs or ill children go to the

Malki Foundation wing at Yad Sarah, which is brightly painted and child-friendly, to borrow walkers, wheelchairs, standers (to help keep youngsters upright), hospital beds, bath inserts and lifts for as long as they need them.

Roughly a third of all families that have benefited from the children's equipment program are from the Arab sector.

"The equipment goes out as fast as we get it," Arnold says.

"We have already spent several million shekels, and the demand is growing through word of mouth." The vast majority of the equipment is not customized, due to the sky-high cost (a specially fitted wheelchair can cost thousands of dollars). But there are exceptions.

"We do our best if the only other option is to keep the child in an institution," Arnold Roth says. "We purchased a customized wheelchair for a 15-year-old girl with cerebral palsy whose parents had been trying to bring her

* A longer version of Michele Chabin's article was published in the Summer 2006 edition of **Philadelphia's INSIDE Magazine**. Reprinted by permission of the publisher/editor, with thanks.

home for years. We currently have a backlog of 35 customized cases.” [Note: *That backlog has grown since this article was published.*]

The fund bases its assistance criteria on the child’s needs, rather than the family’s income, because even upper middle-class families find it impossible to provide the kind of intensive therapies their children need to reach their potential.

“The families that come to us have been everywhere and have nowhere else to go,” Frimet says with a certainty born of experience. “They’re coming after stretching their budgets to the limit, or else they haven’t given their child the therapies he needs and could benefit from. The demand for help is huge, and we’re afraid the fund will dry up. If this happens, I don’t know what we’ll tell these parents.”

Although the families assisted by the Malki Foundation rarely meet the Roths in person, their respect for the Roths and the people who support the fund knows no bounds. “I found the fund on the Internet,” says a mother named Sharon, who asked that her last name not be published for reasons of privacy.

“I was really embarrassed. I’m a doctor and my husband is a computer programmer. We’d never asked for anything from anyone... They were so nice when I called. Frimet and Arnold were so kind, so approachable. I have no words to say how wonderful they are. I also went to other, bigger organizations, but they were really nasty. Just horrible.”

Sharon insists that “there are ways to give charity and ways not to give it. The Roths know how to give without making you feel ashamed. When you see how they experienced a tragedy and turned it into something good, you have to be amazed.”

Arnold shrugs off the praise. “As a parent, you want to do everything you can for your child. When your child is murdered, there’s nothing to do except to hope that others will smile when you remember her and hear her name. This is our way of making this happen.” ■

Come Visit Us!

IN CELEBRATION OF HER BAT MITZVAH, Eliat Weizman from South Caulfield, Australia, requested that donations be made to Keren Malki in lieu of gifts. On their recent



Eliat Weizman with Keren Malki’s Executive Director, Liat Behr, visiting the Keren Malki Unit at Yad Sarah

Bat Mitzvah trip to Israel, Eliat and her family took time out to visit the Keren Malki Unit at Yad Sarah to see how her generous gift to Keren Malki is being put to good use. They were shown different types of equipment which special-needs children use daily and were able to see first-hand the significance of Eliat’s contribution to Keren Malki’s work.

If you’re considering coming to Israel and plan to be in the Jerusalem area, please consider visiting us. We look forward to meeting you in Jerusalem! ■

Keep Us In Mind

With summer and the High Holidays around the corner, the Malki Foundation plans to conduct its Yom Kippur Tzedakka campaign again, placing collection boxes where charity-minded people can easily contribute their *Kapparot* money. We will be distributing collection boxes in synagogues in time for the eve of Yom Kippur. If you can help us place such boxes in your synagogue, please e-mail Liat Behr, Keren Malki’s executive director at liat.behr@kerenmalki.org. ■



Malki: Help us remember the beauty of her life

Keren Malki needs your help to expand its vital work of assisting Israeli families with a severely special-needs child. Please show your commitment, while remembering a precious life that was lost to a senseless act of terror. **To make a donation**, please fill-out this page and send it to the mailing address that appears below. Some suggested gifts follow...



Malka Chana Roth 1985-2001
May her precious memory be a blessing

- US\$3,000 to sponsor one child's **para-medical therapies for a year**
- US\$2,200 for one **positioning chair** enabling a child excellent posture and the ability to join in regular activities
- US\$1,500 to sponsor one child's **para-medical therapies for 6 months**
- US\$750 to sponsor one child's **para-medical therapies for 3 months**
- US\$650 for one **bath chair** to assist parents in giving their child a bath
- US\$250 to sponsor one child's **para-medical therapies for 1 month**
- Other** (please specify amount and currency).....

Donor's Name (the receipt will be made out to this name):

Email Address:

Street Address:

City / State:

Country:

May we add you to the Friends of Keren Malki e-mail list?

Yes / No

Australia	Israel	United States of America
Australian Friends of Keren Malki Box 16, 393 Wattletree Road Malvern East 3145 Victoria, Australia	Keren Malki (Amutah Reshumah) PO Box 2151 Jerusalem 91023 Israel	American Friends of Keren Malki 736 Grange Road Teaneck NJ 07666 United States of America
Payable to: "UIA RRF" A \$200 minimum qualifies as a tax-deductible charitable donation in Australia. Donations less than \$200 should be made out to "Australian Friends of Keren Malki"	Payable to: "Haruach Hayisraelit" (הרוח הישראלית), a tax-deductible charitable donation in Israel	Payable to: "UJC/Supplemental Giving", a tax-deductible charitable donation in the United States

It's important to ensure your cheque is made payable the right way so we can provide you with a tax-deductible receipt under law. Cheques made out in any other way cannot be assured of a tax deductible receipt. For Australian donors, by arrangement with the Keren Hayesod-United Israel Appeal, funds donated to the Malki Foundation via the UIA are primarily allocated to special-needs children who are immigrants to Israel from countries of distress.