

When Malka Roth, a popular, vivacious 15-year-old, was murdered in the August 2001 Palestinian terror bombing of the Sbarros 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 disabled children at home.

“It was the perfect fit for a girl who was so sensitive to disabled 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. “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 disabled children of this country.”

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

# When You Think of Her

## After the loss of their daughter, a family sets up a fund to assist special children.

By Michele Chabin

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, and just two weeks before her death, she volunteered at a camp for disabled 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 chil-

options.

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

Based in the Roth’s living room, the Malki Foundation ([www.kerenmalki.org](http://www.kerenmalki.org)) reimburses parents for 75 percent to 80 percent of the cost of physical therapy, occupational therapy, speech therapy, hydrotherapy and therapeutic horsetack riding.

“The family can have as many of the five therapies they feel necessary,” Arnold says. “There is almost zero overhead, so this is the most efficient way I know of to directly help the disabled children in this country.”

The fund also loans — free of charge — medical equipment for children in partnership with Yad Sarah, an organization that has long provided equipment to

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NO SMOKING

# WHEN YOU THINK OF HER

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adults. The need is great because the health funds either do not provide the equipment or subsidize it only partially.

Every day, parents of disabled 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 though 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 says. "We purchased a customized wheelchair for a 15-year-old girl with cerebral palsy whose parents had been trying to bring her home for years. We currently have a backlog of 35 customized cases."

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 all families with a disabled child have difficulty securing the help they need, some have a harder time than others.

"Austistic children fall through the cracks a lot," Frimet notes. "Just today,

we had a child who had used up all the therapies he was entitled to through his health fund and his school. Whatever therapy one gave, the other didn't, and the therapies lasted for only six months. What good is half a year of therapy?"

When parents want their high-functioning children mainstreamed into the school system, the authorities often say, "Sorry, you've forfeited what you were entitled to when your child was in special ed."

Frimet relates how a child the fund has helped was mainstreamed into a private kindergarten and was supposed to get a personal assistant. The government made the assignment of an assistant conditional on the child's changing to a state kindergarten mid-year. "This after he'd adapted to his school and his surroundings. You have to wonder what people were thinking."

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."

That changed when Sharon, already the mother of two young children, gave birth to triplets a year and a half ago. Although they were born 13 weeks before Sharon's due date, two of the triplets thrived and now have relatively minor developmental delays. The third triplet, Netanel, has cerebral palsy and other developmental problems.

"Everyone said Netanel's prognosis was totally dependent on the therapies he received," his mother says. "What you put in will determine what you get."

The family's health fund provided therapy once a week, Sharon says, and the special preschool where he is enrolled provided only a limited amount of occupational therapy. "We wanted to give him a push, so we gave him physical therapy three times a week, and occupational therapy, speech ther-

apy and hydrotherapy twice a week. It was costing us between 1,000 to 2,000 shekels per week for Netanel, and the other two triplets need some therapy, too. We were going under. I was working more and more hours. I wasn't sleeping at night because I was so worried about where the money would come from."

Were it not for the Malki Foundation, Sharon says, Netanel would no longer be receiving most of the therapies.

"As dramatic as it sounds, these therapies could mean the difference between his walking or spending the rest of his life in a wheelchair."


When Netanel was born, "they said he would be a vegetable, to put him in a home," Sharon says of the painful conversations she had when her son was still an infant. "But thanks to the intense therapy and Netanel's own will, the kid is starting to walk with a walker. Three months ago, his preschool said he was very cognitively behind. He didn't talk and didn't seem to understand. Today, he says about 10 words and we're working on more. I see so much improvement."

While the money provided by the Malki Foundation has been a godsend, Sharon says, it is the Roth's gentle manner that makes the receiving bearable.

"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." 

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