



Race against time

Jewish community rallies for critically ill Palo Alto girl

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The scent of lavender hangs over the backyard garden of Karen Herzog and Richard Sachs, the sound of wind chimes mingling with the buzzing of bees. Throughout their Palo Alto home, Herzog and Sachs have placed quiet objects of faith: a Star of David made of red foil, a dreidel, amethyst crystals and dozens of brightly colored Tibetan prayer flags. It feels like sacred space.

The prayer flags hang in rows from the living room crossbeams. Each 12-inch-square flannel flag is a hand-decorated wish: "Tiny beauty/Gentle soul/Fly in peace" reads one. "Thank you for showing me the meaning of unconditional love," reads another.

Sophia Herzog Sachs, who cannot walk or speak or chew, who is fed through a nasal-gastric tube, and whose beautiful brown-black eyes reveal little of what lies behind them, is the focus of all this love and prayer.

Sophia was born with Niemann-Pick type A, a rare genetic disorder that affects Ashkenazi Jews. How rare? There are no more than 10 children worldwide with the diagnosis.

Niemann-Pick type A patients lack an enzyme that allows their cells to metabolize lipids. Over time, most organ systems, including the brain and central nervous system, break down from toxicity. The disorder is progressive and fatal, with no patients ever living much beyond their third birthday.

Sophia turns 3 in May.

For more than a year, Herzog and Sachs have been racing against time to save their daughter. In the process, they impacted their community and altered the standard of care for patients like Sophia.

"Western medicine told us there was no way we could win," says Sachs, as he ambles along the broad streets of his neighborhood pushing Sophia in her stroller. "We said, 'This is unacceptable.'"

Rather than turn inward with grief, Herzog and Sachs turned outward, opening the doors of their home to a

community eager to help.

Ever since Sophia was officially diagnosed in early 2003, her parents have launched a campaign worthy of Patton or Eisenhower. Drawing on Western medicine, traditional Chinese medicine and a host of other modalities, Herzog and Sachs recruited a small army of volunteers and health professionals to help them manage Sophia's care, which these days is virtually round the clock.

Is there a "Lorenzo's Oil" out there for Sophia? Not within the arsenal of



photo | joyce goldschmid

Richard Sachs and Karen Herzog with daughter Sophia, who suffers from a rare genetic disorder.

Western pharmacology, according to Dr. Gregory Enns, director of the biochemical genetics program at Stanford University.

"All metabolism disorders are on a spectrum," says Enns. "Sophia is on the severe end, and there's no specific treatment for her. So Richard and Karen have gone to the ends of the earth looking for novel ways to treat the disorder."

That meant a holistic approach, bringing in acupuncturists, nutritionists, kabbalists and other alternative healers. That meant consulting with other experts on lysosomal storage

diseases (of which Niemann-Pick type A is one) and the families enduring them.

And perhaps most of all, it meant drawing on the Jewish community of the South Bay to coalesce around this one fragile life.

Though neither of Sophia's parents is rigorously observant, they both embrace their Jewish heritage and eagerly reached out for help, both logistical and spiritual.

Marlene Salona, a developmental specialist who had been working with Sophia, used her connections at Congregation Kol Emeth in Palo Alto to mobilize help. "When Sophia's condition became critical last year," she recalls, "we coordinated regular meals to the family." Other local synagogues pitched in, among them Congregations Etz Chayim, Emek Baracha and Beth Am.

It started with neighbors bringing home-cooked meals, but it soon grew in scope. "Sophia's name started getting on prayer lists," recalls Herzog. "Then people started coming over. It was like a village coming together, with Sophia at the center."

Says Beth Am Rabbi Janet Marder: "It's quite an experience to be in that home and see a child surrounded by such intense love, hope and faith. Our tradition teaches us to be the hands of God. That means we bring the loving, healing presence of God where it is needed."

The financial strain on the family has taken its toll. Herzog stopped working to care for Sophia full time, and Sachs, a high-tech marketing and communications specialist, had to cut back his work hours. Recently, the family turned to the Hebrew Free Loan Association for financial aid.

Cindy Rogoway of the HFLA had gotten to know the family when she brought over a casserole. That personal connection quickly expanded. "We view ourselves as the safety net

for the Jewish community when facing a difficult life issue," says Rogoway. "People view us as an extended Jewish family when they run out of other options."

Despite all the assistance, it would be a mistake to view Herzog and Sachs as passive recipients of charity. They are



A Star of David, a dreidel and other symbols fill an altar in Sophia's room.

extremely proactive, creating both a healing environment for Sophia and a broader community purpose.

"We are strong warrior Hebrews," says Sachs, who has a 19-year old daughter, Lauren, from a previous marriage. "I'm not surprised by the community help. It goes back to our nature. We've evolved to work in

little tribes, and until 100 years ago, we knew how to do this. Now, we're a medical tribe, a spiritual tribe. We're in a position to take a humble, leadership role."

To that end, he and his wife started Sophia's Garden, a foundation that promotes the kind of broad-based community involvement and holistic approach they've developed for their daughter.

Part of the stated mission of the foundation is to "help create a healing community of information and support for families facing a life-threatening disease."

"We needed a new model of care," says Herzog. "We needed the community, the social service and medical structures to work as a whole system."

Their efforts have impressed everyone they come in contact with, including Enns. "It's remarkable the amount of love they give this child," he says. "Sophia is the best-cared-for child I've ever seen with chronic illness."

Lately, Sophia has hit a few rough patches. She experiences regular apnea episodes, during which she stops breathing, and she continues to have trouble sleeping through the night. She is underweight and sensitive to touch, unable to communicate, barely able to move.

But her parents continue to hope. One Boston-based company, Genzyme, is currently developing gene therapies to treat Niemann-Pick and similar disorders. And though neither Sachs nor Herzog would have ever wished this calamity upon themselves or their daughter, they have truly tried to make the best of things.

"We have more energy than we've ever had," says Sachs. "To help Sophia, we've been in a state of desire, drive and purpose. Creative energy burns very hot in both of us."

Adds Herzog, "I see how hard it is for Sophia to stay alive, and I admire her for every breath. She is a tremendous person, a gift to the world. She is allowing people to come together without judgment, in peace, with open hearts and with compassion. Sophia is my hero." ■

For more information on Sophia's Garden Foundation, visit www.sophiasgarden.org.