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## HOPE AND HEARTBREAK

Neighbors open their hearts to terminally ill child Page 17

# 'Hearts break open'

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## 'Hearts break open'

*Toddler's plight touches whole community*  
by Carol Blitzler / photos by Kate Robertson

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Birth Announcement for Sophia Sachs shows (from left, top) Sophia with her dad, Richard Sachs, with her mom, Karen Herzog, with her half sister, Lauren Sachs and herself.

Every morning Karen Herzog dabs a little oil on her wrists, neck and ears. The oil is called "Hope," and that's what keeps Herzog going -- hope that her nearly 2-year-old daughter, Sophia, will live beyond her 3-year life expectancy.

Herzog and her husband, Richard Sachs, discovered Sophia had a rare, genetic disorder called Neimann-Pick Type A when she was close to 8 months old. It had been rocky from the start -- trouble breast feeding, not sleeping through the night, refusing solid food at 6 months -- but nothing that couldn't be called "normal."

It was their Chinese medical practitioner who said they had a very sick child, and when her herbal teas failed to stop the developmental regression. The couple pushed their Western doctors for answers.

They didn't like what they heard: Sophia had a disease so rare that only eight children in the entire world reportedly suffer from its effects. It's caused by a mutated gene, mainly found in Ashkenazi Jews. There is no known cure. A case had not been seen at Stanford University Medical Center in at least 20 years.

While the doctors offered comfort, Herzog and Sachs asked questions: What helps? What could they do?

In seeking answers for their child, Herzog



Sophia's head is caressed by her father while they listen to guitar music played by a friend. All of her food is supplied now through a nasogastric tube.

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estimated they've contacted close to 250 doctors and researchers in the past year and a half. They've even created a "circle of healing" -- a complex chart that includes traditional and allopathic medicine, spiritual/psychological, family/community support, nutrition/supplements, naturopathy, physical/energy therapies and medical research.

Soon, people in the community heard of the family's need.

More than a year ago, when Herzog and Sophia were participating in Pre-School Family, the other mothers noticed the pair were missing a lot of classes. When they found out about Sophia's illness, they took turns bringing meals to the Herzog home.

Herzog was also involved with Las Madres, a group that promotes breast-feeding. Soon the mothers in that group were pitching in as well. Today, groups from two local synagogues -- Congregation Beth Am in Los Altos Hills and Kol Emeth in Palo Alto -- as well as Parents Nursery School are offering support on a regular basis. In addition, Greenmeadow neighbors, friends, relatives and hospice volunteers have all become part of Sophia's life. And that's not even counting the healing community or the social service agencies devoted to developmentally delayed children (CAR, San Andreas Regional Center) and Pathways Hospice.

Once they meet Sophia, everyone wants to help. After hearing the child had trouble processing foods, one neighbor created an organic garden in the Herzog-Sachs backyard. Another turned the fresh veggies into a soup that Sophia ingests through a nasal-gastric tube.

Robin Modlin, a chaplain resident at Lucile Packard Children's Hospital at Stanford, began a Tibetan prayer flag project. Everyone who visits is invited to decorate a flag with warm wishes for Sophia's recovery. The flags fly gaily over the walls of the family's Eichler home, sending out bright thoughts from the creators.

One friend, Herb Moore, recorded Sophia's



Surrounded by friends and neighbors, Karen tries to make Sophia more comfortable — sometimes needing help with her.



Deborah Mils, a graphic designer and friend of Richard's, makes Sophia's special formula — a mix of supplements, banana, goat's milk, goat's yogurt and Chinese herbs. "I've been doing this everyday since February 3rd, when she was diagnosed," she says.



Sophia enjoys many visitors who talk and play with her. Here, volunteer Sonja Swenson, a seventh-grader at Castilleja School, plays with Sophia's hand while her mom watches them bond.



vocalizations over several days then wrote music based on the numerical sequence associated with the enzyme the child lacks. Called "Sophia's Garden," the music is available on a CD. A portion of the profits from CD sales will go to the Sophia's Garden Foundation that Herzog and Sachs are setting up.



Sophia responds to an examination by her Doctor of Oriental Medicine and acupuncturist Lucy Hu O.M.D., LAc, while Deborah Quevedo R.N. and Sophia's mother Karen try to comfort her.



Karen lays back with Sophia. After being examined and given acupuncture, Sophia gets a massage from Lucy Hu O.M.D. Behind them is a Tibetan prayer flag with a photo of Karen when she was pregnant with Sophia.

Another friend has

choreographed a dance to accompany the music. Yet another said Sophia has become her muse, sparking her creation of Chinese character artwork.

"In Sophia's short life, she's having a lifetime worth of relationships," Sachs said. Herzog estimates more than 200 people have helped out over the course of the child's illness.

With all the love -- and food and well

wishes -- pouring into Sophia's household, Herzog and Sachs still manage to give a lot back. The couple has learned an enormous amount about integrated medicine, taking from both traditional and homeopathic models, and about community-building. They hope to pass on what they've learned to other families in need, through their foundation and Web site, [www.sophiasgarden.org](http://www.sophiasgarden.org).

Herzog, who has a background in sales, and Sachs, who runs his own marketing communication business are very organized. They have notebooks filled with information, as well as calendars and spreadsheets containing records of who's available to run errands, drop off a meal or give them a caregiving break.

Sophia has never slept through the night and suffers from sleep apnea, so Herzog and Sachs alternate four-hour shifts watching over her each night. In 23 months, Herzog said she hasn't had more than four nights' sleep in a row.

Insurance coverage for home nursing ran out at



Richard Sachs carefully holds Sophia while adjusting her nasogastric tube. Sometimes even small movements can disturb her.

the end of April, but the family is contesting that ruling. In the meantime, there is an ongoing need for providing meals, errand-running, walking the dog, making flags, skilled and semi-skilled nursing, and basically relieving some of the 24/7 care-giving that Sophia requires.

"What's unique and different about Karen and Richard is (they) took the situation and put out the call out to the community because (they) wanted to share this experience. That's what happened. (They) invited the community to come in and share. It's usually a much more private experience," Modlin said. Herzog is quick to acknowledge what that has meant to the couple. "We feel so supported and embraced by our community," she said. "We don't feel alone going through this."



Sophia reacts to a piece of art created by friend Eloth Burnes.

Although Sophia's world is limited by her weak muscle tone, she can make sounds and definitely show likes and dislikes. She prefers old musicals to cartoons on TV, and her favorite music is Fred Astaire or Snoopy's Beatles. Herzog and Sachs must be very careful moving the child, because she's sensitive to any position shifts.

"She seems totally there," Sachs said, adding that typically cognitive function remains while autonomic functions give way. Lately both Herzog and Sachs have noticed that Sophia giggles in her sleep -- something she can't do while awake.

As for Herzog and Sachs, they straddle two worlds at all times, what Herzog refers to as "multi-tasking -- grieving and pursuing cures." She calls the experience "bittersweet -- overwhelmingly painful and overwhelmingly joyous" and asserts neither she nor her husband would "trade this experience for anything."



More than 250 medical personnel and researchers have participated in Sophia's care. Here a conference call to discuss Sophia's condition is held between the Human Genetics departments at Lucile Packard Children's Hospital and Mount Sinai in New York, with friends and neighbors participating.



Richard and friend Herb

Sophia "is a gift. Every moment is a precious one with Sophia. She is exactly who she is and we love her for who she is. Her spirit -- even though her physical body isn't keeping up with her -- is huge. We feel Sophia touching so many people. We're her main caretakers but she's a gift to us and our community," Herzog said.

"I would like her to be here as long as she wants to be here. Hearts do break open. I see a lot of hearts opening."

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