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RICHARD KOCI HERNANDEZ — MERCURY NEWS

Volunteers plant a garden outside the bedroom of Sophia Herzog Sachs.

Girl's garden grows again

P.A. VOLUNTEERS AID EFFORT FOR ILL CHILD

By Kim Vo Mercury News

They say it began with a garden.

Little Sophia Herzog Sachs had been diagnosed with a rare, incurable genetic disorder and Karen Herzog mentioned she wanted an organic garden to

grow the pure food her daughter would need. Herzog's neighbor, Penny Ellson, organized a crew and got to work.

That was three years ago. On Saturday, neighbors in Palo Alto's Greenmeadow community gathered again for the annual planting, adding lettuce, chives,

ever seen."

- DR. GREG ENNS
OF LUCILE
SALTER PACKARD
CHILDREN'S
HOSPITAL

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strawberries and pumpkins to the vegetable patch that will sprout outside Sophia's bedroom window. The garden has created other nourishing offshoots. Today, prayer flags hang throughout the Eichler home. Volunteers bring food, run errands, offer massages. A network of volunteers monitor medical research that might help Sophia. Clergy in monasteries as far away as Tibet and Bulgaria include her in their prayers.

The family estimates that 300 to 500 people have helped in some way with Sophia's care.

"There's a lot of mothering going on at our house," said Herzog, 43.

Sophia has Niemann-Pick Type A, a genetic neurological disease so rare that Sophia's is the only case her doctor — Greg Enns of Lucile Salter Packard Children's Hospital — has ever seen. It causes an enzyme deficiency that

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"It's overwhelming to come into their living room: Oh my god, look at all this love."

GARDEN | Labor of love aids ill girl

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interferes with her cells' me-tabolism. She cannot talk, walk, crawl or swallow. The disease is so deadly that most children only live to their second or third year. Sophia celebrates her third birthday May 22. Her parents credit that

third birthday May 22.
Her parents credit that
milestone to their comprehensive approach, one that
incorporates Western and
Eastern medicine, spirituality, family and neighbors.
They are hoping that model
can be used by other families
caping for gravely ill chil. caring for gravely ill chil-

Enns doesn't claim this novel approach is helping Sophia — he can't compare what her health would be like without the herbalists, prayer flags and so on — but it hasn't seemed to hurt. He did note that her parents' devotion is remarkable. "She's absolutely the best-

cared-for child in such a sit-uation that I've ever seen," Enns said. "She's taken care of exceptionally well, and that's helped prolong her

Sophia's health is precari-ous. In January 2003, she kept choking, and her par-ents took her to the hospital where doctors said it was time for hospice care.

Doctors outfitted her with a feeding tube. Since she cannot chew and swallow, cannot cnew and swallow, her family and caretakers cook, then liquefy, meals such as rice and beans or lung-brain tea, made of tree bark and a fungus that grows on caterpillars. The nutrients can pass through the feeding tube that runs from her nose to her stom-

ach.
The girl with long eyelashes and pencil legs has good days and bad ones. She likes to watch movies, said her father, Richard Sachs, and the taste of berries on her tongue, even though she cannot swallow them. She hates having blood drawn and her weekly acupuncture, though she delights in the massage



Olivia Ellson, 4, waters an organic garden Saturday at the Palo Alto home of Sophia Herzog Sachs, who suffers from an incurable genetic disorder. Community members helped plant the garden, now in its third year.

that follows. Though she can't speak, her father can tell she enjoys the visitors who troop through her

"She gets bored by her worried parents," Sachs, 51, said. He has another daugh-

said. He has another daughter from a previous relationship.

Volunteers help Herzog and Sachs, too. Several synagogues and mothers' groupshelp prepare meals so the overwhelmed parents can keep up their strength. Amy Friedman, who approached the groups, said it was tough for some people to see a child so sick. But it helped to step inside the house and see it adorned with prayer flags it adorned with prayer flags colorful rectangles in-spired by Tibetan prayer flags, hung across the ceil-

ing, stretching into the front yard, each one made to show support for Sophia. There are hundreds of them. "It's overwhelming to

"It's overwhelming to come into their living room: Oh my god, look at all this

love. This one little girl inspired all this," Friedman said.

IF YOU'RE INTERESTED Herzog Sachs and the foundation she inspired, go to www.sophiasgarden.org

Contact Kim Vo at



Sophia Herzog Sachs, 2, rests in a stroller while Palo Alto community members plant an organic garden that produces food for her.

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