# Honolulu Star-B

**MONDAY, DECEMBER 25, 1989** 

THE PULSE OF PARADISE

This is the story of an infant who has brought joy, inspiration and a silent message of love to all who cross her path.



And a little child shall lead them.

Isaiah 11:6

By Rod Ohira

"Naomi's Big Adventure," a KomaRoss rideo production, is a hilarious look at one day in the life of an 11-month-old andicapped infant through the eyes of her father.

The homemade film, produced by Richard Ross and baby-sitter Ruth Komatsu, says a lot about Naomi. There is nothing sad about her, and laughter is a product of the joy she represents.

Naomi Keiko Ross was born on Jan. 20

mosome disorder. She is blind, deaf and has club feet.

Her chances of survival are slim because of other neurological damage, such as a heart defect and lung damage. Trisomy 18 infants rarely live for more than a few months.

But Richard and Debbi Ross of Kaimuki feel they have been blessed with a "gift from God."

"Naomi doesn't do anything, but I can look into her face for hours," Debbi said. "It's so peaceful. I see a pure heart that just pulls love out of you.

"She can't see me but I know she sees God." parents, relatives and friends.

"She is really a gift to all of us, a living symbol of Christ's presence," said Manoa Valley Church pastor Don Asman. "Our (church) community has really rallied around her."

Naomi has touched the hearts of many people, including some who have never met her, with a silent message of love. They have responded by sacrificing time and profit to help someone in need.

"She has caused people to think about life," Debbi said.

Komatsu, a teacher at Pearl Harbor Elementary School, and Darrel Oniwa, a sales representative, volunteer time To others, Naomi may seem imperfect. But to Richard and Debbi Ross, Naomi is the perfect critical

#### NAOMI: An imperfect child is a perfect gift

Continued from Page A-1 to sit with Naomi

Both have gained something from their relationship with the

"I felt drawn to Naomi," Oniwa said. "I cannot communicate with her but through her I see how precious life is whether a person is normal or not."

Komatsu invited Debbi to bring Naomi to school in May and the experience, she said, was a positive one for the students.

"That's why we call her Naomi the evangelist," Komatsu said. "They came away caring more, I think, for students in our school who are handicapped. It was very positive.

"They even drew pictures of Naomi as a grown-up and we sent them to her."

The Rosses realized shortly after Naomi was born that their car was not large enough to transport their daughter and all her special equipment. Their car also did not have an air conditioner, which Naomi

Richard Ross, a cooperative placement specialist for the University of Hawaii, shopped around without success for a van he could

Frustrated, he decided to go one

step beyond and wrote to the auto corporations

Ron Ushijima, the Hawaii representative for Mazda Motor, of America, was touched by Ross'

"From a human standpoint, they were taking on something a lot of people would shrug off, knowing that the child was going to die," Ushijima said. "They were preserving a life. The least we could do was try to get them a van.

Ushijima arranged a deal with the help of Jeff Boyt of Mazda's regional office that allowed the

Rosses to purchase a van at dealer cost plus \$100 for paperwork.

The Rosses also were shopping around for an air conditioner since Naomi's room needs to be kept at a

certain temperature.
Glenn Ogasawara of Pacific Island Air Conditioning heard about Naomi through a friend, Terrance

Arakaki. Ogasawara donated an air-conditioning unit to the Rosses.

"Naomi has inspired a lot of faith and love in her parents," Ogasawara said. "It makes me feel good to be able to help."

The medical staff at Kaiser, the

Rosses say, also have been very

Whoever welcomes one such child for my sake, welcomes me.

Matthew 18:5 "Nao in Japanese is the root of (naosu) which means to repair or fix, and mi means beautiful," Debbi Ross said. "In Hebrew, Naomi means pleasant."

The name is especially meaningful to Debbi, who considers her change in attitude "Naomi's first

was feeling resentful," Debbi said of her initial reaction to being pregnant. "We had been married for only 10 months and it meant changes in my life that I wasn't ready for."

In the fourth month of Debbi's pregnancy, the Rosses learned that their daughter would not be

"We were shocked and stunned," Debbi said. "I never thought our child would be any-

thing but normal.

"There was an option to terminate the pregnancy but we wanted to talk it over, read and pray before making that decision."

They made their decision after

praying that day.

"We both felt God was giving her to us as a gift," Debbi said.
"Naomi is imperfect, but for us,

she is the perfect child."

Naomi weighed slightly less than 3 pounds at birth and has gained only six pounds since. Her physical condition remains fragile.

Naomi is fed through a tube and has limited muscle control. She cannot roll over or even lift her

But she does smile.

"Quality of life," Debbi said, "is not in what you can do but in what value there is in just being alive. When people meet Naomi, they understand."

At Manoa Valley Church's Sun-day service last week, Naomi played the role of baby Jesus.

In the eyes of those who know her, it was the Lord who did the casting.

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"Naomi doesn't do anything, but I can look into her face for hours. It's so peaceful. I see a pure heart that just pulls love out of you.

Debbi Ross Naomi's mother



By Ken Ige, Star-Bulletin

# Naomí

## My Delight

I delight to do thy will, O my God; year thy law is within my heart.

Psalm 40.8

By Ken Ige. Star-Bulletin

In Japanese, nao means repair and mi means beautiful. In Hebrew, the name means pleasant. This sign hangs on the wall of the Ross' bedroom.

# Couple face handicap in handling child

# ☐ Naomi was born deaf and blind due to a rare ailment

By Rod Ohira

Richard and Debbi Ross of Kaimuki have learned to care for their 11-month-old daughter, who was born with severe birth defects due to a chromosome disorder, through information provided by support groups.

"It's pretty much learn as you go," said Debbi, who quit her full-time job to care for her daughter Naomi.

Naomi cannot see or hear and has heart and lung problems and club feet. The defects are caused by a chromosome abnormality called Trisomy 18. Information on caring for Triso-

Information on caring for Trisomy 18 infants is limited because babies who suffer from the condition do not live very long.

Trisomy 18 is the second most common cause of multiple birth defects in infants, wrote the late Dr. David W. Smith in "Recognizable Patterns of Human Malformation."

Trisomy 18 or Edward's Syndrome occurs once in every 4,000 to 5,000 infants born alive, according to an informational pamphlet for families published by Childrens Memorial Hospital of Omaha. Neb.

Fifty percent of infants with Trisomy 18 die within a six-month period following birth; 90 percent do not survive their first birthday.

It is not known what causes the faulty chromosomal distribution, resulting in trisomy, but on the average, one in every 200 babies has some kind of chromosome abnormality.

Chromosomes are tiny, threadlike structures within each body

Each cell has 22 pairs or 44 chromosomes, containing hundreds of genes that determine an individual's appearance and body functions, plus two additional sex chromosomes that are different in males and females.

Males have "X" and "Y" sex chromosomes while there are two "X" chromosomes in female cells.

Too much or too little chromosomal material does not allow for normal development during pregnancy

Down's syndrome, for example,

is the most common form of trisomy. The condition can be traced to chromosome abnormality in the 21st pair.

Trisomy 18 involves an extra chromosome — three instead of two — on the 18th pair.

None of the genes in the extra chromosome is abnormal or defective in any way.

But the mere presence of the extra normal gene results in birth defects and other medical problems.

Trisomy is not inherited and the extra chromosome is not the result of anything under the parents' control.

The extra chromosome arises during the formation of the egg or sperm prior to conception.

Environmental factors, such as illness during pregnancy and the consumption of alcohol or drugs, have not been implicated in causing the condition.

Information on care and services available for Trisomy infants may be obtained by calling Greg and Terri Gangwes of Hilo at 969-3118.

Terri Gangwes is chairperson of the Support Organization for Trisomy (SOFT) in Hawaii. I'll always remember how pure Naomi looked while sleeping. She could draw people to her, making us all evangelists.

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Ruth Komatsu, family friend of 5-year-old Naomi Ross, who died Saturday of a birth defect



Special to the Star-Bulletin

# Manoa girl leaves behind silent inspiration for all

Naomi survived for nearly 6 years, despite an abnormal chromosome

By ROD OHIRA Star-Bulletin

AOMI Ross was a perfectly innocent child in an imperfect body.

A lead-in to the Honolulu Star-Bulletin headline "Naomi" on

Star-Bulletin headline "Naomi" on Christmas Day 1989 said a lot about what she accomplished in this world.

It read, "This is the story of an infant who has brought joy, inspiration and a silent message of love to all who cross her path."

Naomi could not see, speak, hear or walk.

She was born with severe birth defects caused by a chromosome abnormality known as Trisomy 18.5 uch infants rarely live for more than a few months.

But Naomi, who died Saturday, came within 96 days of celebrating her 6th birthday Jan. 20.

Naomi died about 2½ hours after her parents, Richard and Debbi Ross of Manoa, brought her home from Kaiser-Moanalua Hospital. Naomi had been battling pneumonia for two weeks.

"We had her with us for six years," Debbi Ross said, "and now we look forward to seeing her again one day."

Naomi required around-the-clock care and her parents provided that with help from friends.

"We know her spirit has been set free from her body and that she is back home in heaven with Jesus," Debbi Ross said.

Ruth Komatsu, a close family friend, said, "I'll always remember how pure Naomi looked while sleeping. She could draw people to her, making us all evangelists."

Richard Ross thinks Naomi might be sharing the following message with

Jesus about the many friends and relatives she leaves behind:

"I can see the finish line! This weak body, strong in you, Lord, has run the race you've given me. Thank you for loving me and for running with me these six years.

"I hear the encouragement of the saints and angels! Oh, the joy of being a child of God! To know the pure laughter of the redeemed. "I know Mommy and Daddy are

"I know Mommy and Daddy are watching me as I run these last few steps. Do not be afraid, my future was planned for God's glory. I am running and cannot look back now.

"Heaven fills my pounding heart. I can see the finish line! I am free!"

Besides her parents, Naomi is survived by younger sister Hannah; paternal grandfather Marine Ross; maternal grandparents Thomas and Amy Shiroma; and great-grandmother Suki Yamagiya.

De l'Services will be held at 6 p.m. Oct. 29 at Central Union Church.