

# Christmas reunion made possible for family

By JAN LOVELL

Like so many other families, the Roy Brinkleys want to share the Christmas holidays together at home.

But unlike many other families, the Brinkleys' simple desire to have their family together for the holidays means making special and costly arrangements with the University of Oregon Health Sciences Center in Portland.

Their 4-year-old son Jamie has been under intensive care at the hospital since Aug. 28. He is paralyzed from the neck down.

Jamie was born with a genetic enzyme deficiency called "Morquio's Disease." This extremely rare disease causes deformation of the bones and abnormalities in the body tissues. The condition had not been positively diagnosed until this summer, even though his head began to fall back and his feet began to turn under.

Jamie will eventually die from the disease or its complications. Since July, Jamie has had to fight even more difficulties. One day he fell off his favorite toy motorcycle. That fall severely damaged his spinal column, causing paralysis in his left side.

An attempt at corrective surgery on Aug. 28 failed and Jamie Brinkley has been totally paralyzed from his neck down ever since.

Although he was taken out of the intensive care unit almost two weeks ago Jamie is still under 24-hour care. He must use a respirator and breathe through a tube in his throat.

Jamie's family has been a big part of that 24-hour care. His mother and father, Sherry and Roy, have spent many hours commuting from their home in Lebanon to the hospital. Sherry even stayed in a mobile home in the hospital parking lot the first

few critical weeks after the surgery.

Roy's parents, Duncan and Bea Brinkley of Boring have also been almost daily visitors. Roy's brothers and sisters, Carl, Vona and Gwen have been able to visit Jamie also. All are graduates of Sandy High school, and, with the exception of Vona, still live in the Sandy-Boring area.

But Jamie's family has decided that it's time for him to come home again. They've been planning since October to have Jamie home in time for Christmas day. "We've just got to have him home for Christmas," Sherry said. "We spent Thanksgiving here and we don't want to have to do that again. We just want to be one family again."

That simple wish of wanting Jamie back home again will be a costly project for the family. As long as he is in the hospital, the insurance covers the costs. Once Jamie goes home, however, the Brinkleys must pay twenty percent of the cost.

The Brinkleys' share of the cost will include at least \$1,300 a month for two nurses' wages plus the initial cost of the equipment including the respirator, a heart monitor and a suction machine.

The Brinkleys' share of just the nurses' wages will amount to more than Roy makes as a joiner at Champion International in Lebanon. Jamie is not eligible for social security or the Crippled Children's fund.

"The kids have looked into every possible way to get financial help for Jamie," said Duncan Brinkley. "The thing that I guess sours me about this is that if Roy weren't working or if they weren't married, then Sherry could get help from the government.

"There's something wrong with a system when people who work hard and pay their taxes can't even get some help when they really need it."

Some friends have taken the initiative to collect some money for Jamie by setting up donation cans in different parts of the city. A fund has also been set up through the Brinkleys' church in Lebanon. Donations may be sent to the "Jamie Brinkley

Fund" in care of the Lebanon Chapel, 723 Park, Lebanon, Oregon, 97355.

Sherry has been staying in the same room with Jamie to learn how to help take care of him when he goes home although the two nurses will still be needed for the 24-hour care. Jamie's brother, Bobby, 12, and sister Denise, 7, will also be helping out at home.

"They've learned a little bit about what they can do to

help," Sherry said. "And they're very excited to have him home."

Jamie was scheduled to go home Dec. 16, but he caught a cold and the family and doctors thought it would be better for him to get well in the hospital. "The kids were really disappointed that he couldn't come home on Saturday," Sherry said. "But I'm just thankful it happened now instead of later. But we still are

determined to have him home by Christmas day."

Sherry said Jamie will have a quiet homecoming with just family and possibly some friends. "His little buddy across the street is very anxious to see him, I know, though," Sherry said. Jamie's only request for Christmas will also be waiting for him — a little white table with apples painted on the top. "Jamie's mind hasn't been affected by

this at all," Duncan said.

"He wanted that table last year for Christmas, but his parents told him maybe he could have it this year. He sure hasn't forgotten about that promise."

"His mind is still so alert," Duncan said. "And he's sharp enough to know how to bargain with the nurses."

"We're just so thankful he is still so alert," Bea said. "There are some children in there who are just vegetables

and don't even know who their families are."

Doctors have given Jamie two months to two years to live. Pneumonia and massive infections are his biggest potential enemies.

Duncan said doctors also told the family taking Jamie home will also probably make his life shorter than if he stayed in a hospital. "The family decided that quantity isn't the same as quality," Be said.



DUNCAN AND Bea Brinkley of Boring hold a photograph of their grandson Jamie, inset, who has been in intensive care at the University of Oregon

Health Sciences Center in Portland since Aug. 28. He has a genetic enzyme deficiency that will eventually kill him and he is also paralyzed after

falling from a toy. His family is hoping to bring the boy, who must have constant and costly care, home in Lebanon, Ore. by Christmas.

Staff photos by Jan Lovell

## Life expectancy has increased by three years

Life expectancy in the United States has reached 73.2 years of age, federal government studies show.

The figure is based on studies made during 1977 and represents almost a five-month increase for babies born the previous year, according to the Department of Health, Education and Welfare.

The statistic represents a three-year expectancy increase for babies born in 1968.

The HEW report showed that white females born in 1977 can expect a life span of 77.7 years. White males were given a 69.9 year life expectancy.

For non-white females, the life expectancy rate was reported at 73.8 years and non-white males have a life expectancy of 65 years.

The National Center for Health Sciences reported a marked decline in the mortality rate. The decline was attributed to absence of an influenza epidemic in 1977, the study said.

Public officials anticipated a swine flu epidemic, which

did not materialize, and only scattered outbreaks of A-Victoria flu strain were reported.

These factors produced a 20 percent decrease in the death rate caused by influenza and pneumonia. The

death rate of 8.8 per 1,000 population is the lowest annual rate recorded in the United States, said HEW officials.

Infant mortality rates also decreased during 1977. Reports showed a figure of 14

deaths for every 1,000 live births. This figure is down from the 1950 mortality rate of 30 deaths for every 1,000 live births.

The statistics are based on a 10 percent sampling of deaths. If they prove ac-

curate, 1977 will be the only year infant mortality had dropped.

In ranking causes of death, the report shows heart disease as the leader, although the number of fatalities has decreased.

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