

## JW HOUSE TO AID FAMILIES OF YOUNG CANCER PATIENTS

# Because of boy's spirit, doctor's dream comes true

By L.A. Chung  
Mercury News Columnist

On the wall of Dr. Alan Wong's cramped office is a giant framed check for \$10,000 signed by Jan-Willem Knapen, one of his patients.

A small note is pasted on it like an affirmation:

"The check that started it all."

"All" means the construction of Jan-Willem's dream – The JW House – which had its ground-breaking Friday afternoon on the new hospital campus of Kaiser-Santa Clara. But "all" means much more than just that.

It could mean, "all this stuff," crammed into Wong's office. All the fundraisers, from winter carnivals to dinners at the Plumed Horse that helped build the dream. When it comes to J.W. it could mean all the gifts, all the memories, all the fun.

"Fun" may not be the word we think of when considering a doctor and his terminally ill, 16-year-old patient.



Dr. Alan Wong, an oncologist at Kaiser in Santa Clara, in his office Friday, March, 30, 2007.

But you have to know Jan-Willem and Wong.

Wong, a pediatric hematologist-oncologist, was stunned three years ago when his Belgium born, teen patient arrived bearing a big, blown-up check for \$10,000 with the notation, "Our Dream Project."

It was for the house that Wong mentioned in a moment of frustration, wishing he had a sanctuary to offer the families of his young, gravely ill patients. Where they could stay while the patient was undergoing treatment at Kaiser. J.W. knew what it was like not to have such a place.

But when Wong was confronted with the huge check, he was flummoxed.

"I'm a doctor," Wong said. He knew nothing of non-profits, or 501(c)(3) designations or fundraising. And yet he thought if a sick kid was able to raise 10 grand by appealing to his friends, family – what else could Wong do?

With enthusiasm reminiscent of Mickey Rooney and Judy Garland ("Let's put on a show!") they pulled together a simple board of J.W.'s parents; Barbara Mount, his music teacher from Bellarmine; his Kaiser social worker and a few friends.

They produced a kind of modern-day barn raising: Pizza dinners, Belgian beer-and-fries events, art auctions of J.W.'s doodles, fancy Saratoga wine and fashion shows. And they got lucky. Helen Marchese-Owen, a community fundraising dynamo, whose family once farmed the land on which Kaiser's new campus sits, joined the board. Kaiser pharmacist Bond Kou, struck by a meeting with J.W., raised \$3,000 in pledges to bicycle around the bay. The late former Kaiser executive Walter K. Palmer donated \$25,000 in June. TBI Construction, which is building the house, got other builders to donate services.

"I've never had so much fun in my life," Wong said. Much of it because of J.W.

That \$10,000 check turned into \$1.5 million. It seemed like a sheer

outpouring of love for the sunny boy from Belgium.

From the beginning, Wong could tell J.W. was different. The young man showed wisdom beyond his years in looking death in the face with maturity, grace and unfailing humor.

"J.W. had a condition from which people die," Wong said simply. "He made friends with people easily. And in the face of his own mortality, he had the ability to separate out from focusing on himself to try to do some good."

Simple and practical

"It was a very simple thing to want to build a house," said Wong, "and a very practical thing."

The reality of cancer treatment often means families must travel long distances and sometimes leave other children at home. In some of the most wrenching times of their lives, they desperately need a little peace, a little privacy, a little comfort. Instead they are shuttling between motel and hospital, spending days jammed into narrow hallways, filled with the bustle and flow of a hospital brimming with critical business.

You must be a man of unusual fortitude to be a doctor for cancer patients as young as one month to 21 years old, I said. Not really, Wong said. His patients, 75 percent of whom are successfully treated, teach him a lot.

Several years ago, he had a patient who was 7 or 8 years old, Wong said. She had neuroblastoma, a stomach tumor. "It was bad, bad cancer. She almost died during the bone marrow transplant." But she made it. "And then cancer came back, very fast.

"I asked myself, 'Am I doing the right thing?'" The patient had to go through so much. The treatments were so painful. He asked the family, "Was it worth it?"

"You give me a few more months to hold her hand," her father replied. "You give me a few more months to go to school with her. It's worth it."

Wong changed his mind after that. "It's not how long you live. It's the quality."

It was the same with J.W., who underwent radiation, chemotherapy, experimental therapy and grittily, amazingly, came back from two comas. He died Aug. 3, 2005.

"I still can't tell you why this happened," his mother, Anne Marie Knapen-Asnong, said Friday afternoon "and why people jumped on board – for this movement of the heart."

Even now, 19 months after J.W.'s passing, his inspiration is all over Wong's small office. In one corner is a cotton-festooned, cardboard

snowman used in winter festival fundraisers. Atop a shelf is a box full of blue rubber JW House wristbands. Behind his chair is a grocery bag full of recyclable soda cans and water bottles. They're redeemable at 5 cents apiece, you know.

If you can make \$70,000 on little rubber wristbands, who says redeeming cans is not worth it?

Above the giant framed check, there is artwork by J.W., like the ones he auctioned a few years back. They are brightly colored cartoon-like characters, each one of them spelling out his words, "Never, ever, give up."

JW House is scheduled for completion at the end of the year – four apartments, a communal dining room and a garden will bloom on the land that was Helen Marchese-Owen's home for 38 years.

Wong wants to put the big framed check on the wall, the check that "started it all."

For all these families, when facing the frightening and terrible unknowns, the house will be a quiet place infused with the spirit of J.W.'s gifts: All the memories, all the fun.

See [www.jwhouse.org](http://www.jwhouse.org). Contact L.A. Chung at [lchung@mercurynews.com](mailto:lchung@mercurynews.com) or (408) 920-5280.

Dr. Alan Wong, an oncologist at Kaiser Permanente in Santa Clara, in his office Friday, March, 30, 2007. He was stunned three years ago, when one of his teenage leukemia patients came to a routine appointment with a big, blown-up check for \$10,000, made out to Dr. Wong, with a notation, "Our Dream Project." The check, from Jan-Willem Knapen, sits framed on the wall, in his cramped office, which has been a ad-hoc headquarters for the JW House campaign. The house, meant for families of cancer patients to stay while their relative received treatment, broke ground Friday with completion scheduled for the end of 2007. (Patrick Tehan/Mercury News) ( Patrick Tehan )