

INSIDE CONNECTION

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**JW Knapen**

1988 – 2005

“Please don’t mourn about me. Instead, be happy, laugh, shine and be grateful.”

More than 900 friends, family and supporters gathered to say goodbye to KP SCL patient, JW Knapen, at his memorial service on August 18, 2005. Many of them were physicians and staff at KP SCL who came to know and love JW during his fight to overcome brain cancer. His legacy will live on at KP SCL—the JW House is expected to open at the same time as the final phase of the new Hospital in 2007. Below we celebrate a unique individual.

The house that JW built

by Thomas Ulrich

“JW changed my life,” says Alan Wong, MD, a pediatric oncologist at KP SCL. “He taught me to be a better doctor. I feel it. I know it.”

Born prematurely on Sept. 22, 1988, Jan-Willem Knapen spent a lifetime challenging himself and others to fulfill their promise as patients, parents and practitioners. Following a six week struggle in a neo-natal intensive care unit, JW, his parents and the hospital staff prevailed. And Jan-Willem experienced the meaning of a rallying cry that would carry him for the rest of his days.

“*Never ever give up,*” he said many times during his short but significant life.

Diagnosed with leukemia at a clinic near his home in Leuven, Belgium at age four, doctors prescribed a therapy that destroyed trillions of red blood cells, many infection-fighting white cells and platelets that were essential for clotting his blood. The cure proved to be as fatal as the disease.

Nearly a decade after doctors treated him for leukemia, JW and his family, now residents of San Jose, learned that three brain tumors triggered by his

chemotherapy had provoked a recent bout of seizures. It was Nov. 2002 and JW was fighting for his life while teaching others to embrace what it means to live.

“The first time I met the family, I told them he was dying of cancer,” Dr. Wong says. “A lot of the time, I told them bad news, unpleasant news. Yet JW always found time to laugh.”

His sense of humor was infectious. Whoopee cushions, silly string or a comment like ‘you don’t look anything like your ID badge—you are much uglier

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in person,' always earned a laugh. A joke, a smile or a kind gesture won the heart of nearly every person he met during his two-and-a-half year battle with cancer.

Keeping the faith

"The difference between JW and other patients is that he offered me his friendship," Dr. Wong says. "Most of our patients are fighting for their lives and we're fighting along with them. We become very close, but during the fight not many say, 'Oh! I'm going to care for you too.'"

Dr. Wong recalls many touching stories like the one about JW stopping by his office to wish him a nice vacation. But imagine his surprise when JW presented him with a check for \$10,000. It was just two months after an informal conversation they shared about the oncologist's wish to provide families with a place to stay while a parent or child is treated at KP SCL.

"We have to do something for the families of sick children," JW said shortly after he handed him the check, "but my goal was to give this to Dr. Wong because he has done so much for me."

"It was this selfless act that inspired me and others to plan to eventually build the JW House," Dr. Wong says. To date, the JW House Fund has collected more than \$600,000 toward its \$1,200,000 goal.



JW's gift to Dr. Wong and the community reaches far beyond providing a place for families to gather when a loved one is treated for a disease that requires an extended KP SCL hospital stay. Comprehending his diagnosis, JW

agreed to try a number of new medical procedures and drugs.

"Few people witnessed his courage," Dr. Wong says. "He believed he could help others through his illness. He participated in medical studies because he wanted to teach me and other physicians more about his disease."

Teaching his elders

"I watched him hurt, fear and breathe just like the rest of us," Vicky Prapong, child health specialist says. "It was what he did with those emotions that set him apart from other patients. He decided to live and hope and love instead of just waiting to die."

While detachment is often perceived as a virtue among scientists, expressing emotion is vital to the healing art.

"Somehow, we learn to keep our professional distance," Vicky says. "JW taught me to give of myself and that I must feel deep sadness to experience deep joy."

"While I can say we all loved to hear him laugh, sometimes there were moments when tears filled the air. His tears and our tears mingled together. There was sadness and pain because the cancer was back; the medicine didn't work; he was going to die. It was during these difficult times that we experienced our humanity."

The moments of deep joy balanced the deep sorrow. Last March, soon after KP SCL dedicated the ground for the JW House, Jan-Willem confided to his mother, Ann Marie Knapen, that it was the happiest day of his life.

When asked about his exuberance, JW would often say: "What am I going to do? Sit around and wait to die?"



Dr. Wong with JW Knapen.

"Sometimes it felt like he was the one teaching me to cope," Vicky says.

Never ever give up!

Before he returned to the hospital for the last time, JW spent a month at home with his family. "It was a great gift to be a family again," his mother says.

Before he died, his family vowed to carry on his dream of the JW House.

"Many times I asked Jan-Willem to work hard at school," his mother says. "I expected him to keep his promise. He can count on me to live up to mine."

Generous in life, Jan-Willem planned for the well-being of others after his death. He raised money for the Belgian Cancer Society and donated his brain to medical science so that researchers could explore ways to cure the disease that took his life.

"He's an inspiration to us all," says Bernadette Loftus, MD, KP SCL physician-in-chief. "Because his idea is so right and has such great community support, we were moved to provide the land for the JW House and plan to cover half the operating expenses. I have two sons. I can only hope that they contribute to the betterment of the world during their lifetimes the way JW contributed during his."

For more information go to www.jwhouse.org.

Farewell, Andrea



Andrea Leiderman
1957 - 2005

KP SCL said goodbye this month to another dear friend, Andrea Leiderman. Andrea passed away on Sunday Sept. 11, having bravely battled cancer for the past year-and-a-half.

Andrea will be sorely missed by the KP family. As Community and Government Relations Manager for close to a decade, Andrea was instrumental in getting the necessary government approvals for our new MOB and hospital at Homestead. Andrea's spirit will live on through the impressive body of work and many, many people, friends, and loved-ones she leaves behind.

The Leiderman Family has established a fund in Andrea's memory at Stanford University under the auspices of the Haas Center for Public Service, to support student service and research with underserved Bay Area youth and adolescents. Donations in her memory may be sent to:

**Andrea Naomi Leiderman
Fellowship Fund
for Stanford Undergraduates**
Stanford University Gifts Processing
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