

Vicky's Story: Put The Patient First

Vicky is channeling her heartbreak of losing a dear friend and mentor to bladder cancer into a passion to improve the journey for others impacted by bladder cancer.



RESISTING ALL SIGNS

For eighteen years, Hans was Vicky Wang's mentor, business partner, and father figure of sorts. They traveled the globe and worked very closely together while they were stationed at their company's regional headquarters in Taiwan. Hans did not speak Mandarin, the local language, so Vicky, who is fluent in English and Mandarin, served as his translator.

Every year, the company required an employee physical. For at least ten of those years, Vicky translated to Hans that the Taiwan-based doctor found blood in Hans' urine sample. He didn't have typical environmental or genetic risk factors for bladder cancer, but Hans did tend to dehydrate due to his heavy travel schedule. Assuming the test results indicated a bacterial infection, the doctors often prescribed antibiotics for Hans. He took the antibiotic but never returned for a follow-up or heeded their recommendations for further tests like cytology (looking for suspicious cells in a urine sample).

Hans was a stubborn man who assumed that his health was always at optimal levels for his age. As a trained medical professional, he tended to self-diagnose himself, much to Vicky's chagrin. "It was a major hassle just getting him to visit the hospital to provide a urine sample," she remembers.

Vicky also had specialized training; she was a pre-med student and later focused on public health. She knew that gender played a role in how health issues were perceived. She also knew that red flags and healthcare recommendations should be taken seriously.

In 2015, Hans had difficulty passing urine. At 70 years of age, he self-attributed this to benign prostate hyperplasia (BPH) and refused to see a doctor to confirm his assumption. She pressed him, "Are you sure this is a prostate issue? Maybe you should look deeper into this." By April 2017, his difficulty had worsened. Vicky was scheduled to be away in Europe for a few months, and worried about Hans' wellbeing. She finally convinced him to visit his urologist before she left town. As with all of his medical appointments, she went with him to translate the conversation back and forth between English and Mandarin.

THE WORDS NO ONE WANTS TO HEAR

Tests ruled out the prostate, but did reveal a large, unmovable mass in the bladder. This was the moment that time seemed to stand still. Cancer. Every aspect of Hans and Vicky's lives would change.

In the operating room, surgeons found a large cancerous tumor mixed with stones in his bladder. They also found cancer cells in Hans' urethra, both ureters, and part of his prostate. They removed as much as they could, and his cancer was diagnosed as a non-invasive but aggressive urothelial carcinoma.

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Vicky felt trapped inside a tornado of fiercely negative emotions: fear, anger, depression, loneliness, and guilt. She wasn't surprised though. She thought back to all the times she urged him to visit his doctors or heed clinical recommendations. Could she—should she—have pressured Hans more assertively to take his health more seriously? Or would Hans have dug his heels in further against clinical intervention and prolonged his diagnosis even further?

All those times he shrugged off the warning signs and healthcare advice. His cancer was very likely present back then. What could either of them have done differently? She knew that second-guessing the past wasn't helpful, but the questions kept creeping into her mind.

After surgery, Hans reverted to his usual coping mechanism of stubborn avoidance. "This isn't the lifestyle I want," she recalls him responding to the idea of a radical cystectomy (removing his bladder) as his recommended course of action. "I'd rather die than do that." Vicky and the doctors tried to persuade Hans to no avail.

Vicky felt crushed. He meant so much to so many people. How could he treat himself so callously?

THE EMOTIONAL TOLL

Vicky spoke with Hans' doctors and did her own research. She learned that this aggressive cancer type puts doctors on high alert as it can easily spread beyond the bladder tissue and metastasize through a nearby lymph node. Once bladder cancer cells entered Hans' lymph system, they could settle into other areas of the body and start to grow. She knew that metastasized cancer meant that treatment complexity would increase while prognosis would plummet.

As his caregiver, Vicky wanted to support Hans, but she also felt like he was being selfish in not considering his family and loved ones. He was resistant to contacting other bladder cancer patients, advocacy groups or networks for support, education, or perspective. It just wasn't in his nature to reach out for help; in fact, he saw that as a sign of weakness.

Meanwhile, Vicky relied on support from her tight-knit circle of close friends, and also kept in constant contact with Hans' physicians. But she still felt frustrated, depressed, and exhausted. Hans felt the same way. With Hans emotionally walled-off, Vicky felt like every day was an uphill battle, and every day ended with no progress.



Vicky and her mentor, Hans, circa 2017.

LETTING GO

Hans had begrudgingly agreed to return to the hospital, with Vicky by his side as his interpreter and caregiver, for cancer surveillance tests every few months. He submitted urine samples for cytology tests that entailed microscopic examination for suspicious and atypical cells. He also had a very small camera threaded through his urethra and into his bladder for visual examination in a process called cystoscopy.

Even though cystoscopy was considered the standard of care for bladder cancer diagnosis and surveillance, Hans perceived it to be uncomfortable, scary, and invasive. With her background in public health, Vicky knew that many other men delayed urogenital-related healthcare treatments and procedures due to fear. This fear can be a driving factor in bladder cancer patient non-compliance and can delay life-saving treatment.

At many of those visits, Vicky and Hans learned that his cancer returned. Removing it meant invasive procedures and surgeries, radiation, and chemotherapy.

In spring of 2019, no cancer cells were found in Hans' urine sample or cystoscopy procedure. Even with Vicky's insistence on continuing with his routine surveillance, Hans decided that he didn't need to continue surveillance. Of course, he did need to continue surveillance, but this was his avoidance coping mechanism. He simply didn't want to go back.

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Sure enough, about six months later, Hans' bladder cancer metastasized. Despite aggressive chemotherapy and other treatments, Hans' three-year ordeal with bladder cancer came to an end. Vicky was devastated. She felt that this was the journey that he chose, but it certainly wasn't the journey that Hans deserved.

SHAPING A NEW JOURNEY

Several months after Hans passed, Vicky joined Taiwania Capital Management Corporation, a venture capital company located in Taiwan. Her perspectives in public health and caregiving uniquely qualified her to support AlxMed as one of her first projects. "I believe this was meant happen," she comments. "I am meant to be right here—right now—to fight for an improved patient journey for those suffering from bladder cancer."

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Her personal advocacy includes three elements that would benefit every person impacted by bladder cancer.

First, being mindful of the patient's precious time and making testing and surveillance as convenience and comfortable as possible. Comfort and convenience go a long way in helping to ensure patient compliance with ongoing surveillance methods.

Second, supporting the development of rapid diagnostic and surveillance tools with qualitative and quantitative information that clinicians can use to quickly formulate treatment strategies. The standard of care for bladder cancer has not advanced compared to those used for prostate and breast cancer. Bladder cancer still suffers from a drought of treatment innovations, and enhancements and positive changes are long overdue.

Finally, encouraging bladder cancer patients, caregivers, and loved ones to understand that cancer is not a solo journey of despair. Many people – even strangers – are eager to lend their support and expertise to help ease the burden that comes with a bladder cancer diagnosis.

"I've been on that painful and traumatic journey," she continues. "I want others to learn from my experience, I want them to have a better journey than ours, and I want to ensure that the patient is always front and center."

ABOUT AIXMED

AlxMed helps Pathologists digitize 3D cytology samples in minutes and extract clinical insights in seconds to improve patient diagnosis and care. Our first application, AlxURO, is an Al-assisted urine cytology imaging and reporting software package for bladder cancer diagnosis and surveillance based on The Paris System (TPS). We recently concluded a pilot study and the results were published in Cancer Cytopathology. It is an RUO application at this time.

GET IN TOUCH WITH US

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