

Raine's legacy: Ovarian cancer awareness

by LYN JERDE - SUN NEWSPAPERS

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Lorraine "Raine" Snyder had planned to attend last week's annual meeting of the Minnesota Ovarian Cancer Alliance (MOCA), to inaugurate a fund in her name for the education of physicians about ovarian cancer.

But the disease claimed her life, at age 56, on May 4.

On May 9 - the day after her memorial service at St. Andrew Lutheran Church, Eden Prairie - her husband, Tripp Snyder, attended the MOCA annual meeting in Edina, accompanied by numerous family members and friends.

"We just turned the podium over to Tripp," said Kathleen Gavin, executive director of the St. Louis Park-based MOCA. "And he made some moving, and sometimes hard-hitting remarks."

Among the audience members were physicians, who heard Tripp Snyder declare that doctors had failed his wife when they misdiagnosed her ovarian cancer for almost five years after the symptoms first appeared.

But Gavin said Raine Snyder channeled her anger, and her considerable skills as a public speaker, into educating women, as well as health care providers in all fields.

"She was our ambassador," Gavin said. "Whether it was in a doctor's office or a chemotherapy session, she would educate everyone, everywhere. She was so effective and vibrant, right up to the end."

After her diagnosis, Raine Snyder gave up her career as a human resources specialist to devote her time to educating.

Fellow ovarian cancer survivor Sarah Noonan worked with Snyder on Survivors Training Medical Students.

Noonan said Snyder brought a memorable, but respectful, perspective to the program, in which trained cancer survivors talk about ovarian cancer - its symptoms, its diagnosis and how the survivors were treated by health care providers - with third- and fourth-year University of Minnesota medical students on the first day of their obstetrics-gynecology rotation.

After the sessions with Snyder, Noonan said, students would say, "I'm never going to forget this."

Noonan said she believes she's a beneficiary of programs like Survivors Training Medical Students. Her ovarian cancer was detected early, she said, and she remains cancer free.

Snyder kept on working with Survivors Training Medical Students, Noonan said, even when she was "wiped out" by her cancer therapy.

"She just did an outstanding job," Noonan said, "channeling the energy of her anger into the energy of something positive."

Indeed, there is anger between the lines in "Raine's story," posted on the MOCA Web site (www.mnovarian.org/survivor_stories_raine.htm).

In 1998, she wrote, she went to a gastroenterologist (specialist in the digestive tract) because she was experiencing spasms, severe diarrhea, weight gain around her belly and fatigue.

"I told the gastroenterologist that I had a vivid dream that I had cancer in my belly and I was concerned," she wrote. "He dismissively told me that I did not have cancer. There would be no further discussion of this matter because it was clear that he was the trained expert, and I was only the patient."

According to "Raine's story," the gastroenterologist said she might have Crohn's disease, an inflammation of the digestive tract. He prescribed high steroid doses, which not only failed to alleviate the symptoms, but also made her sicker.

Not until 2003 did an abdominal scan show the presence of cancer. That was when Snyder was given a CA-125 blood test. A normal test reads 0 to 30. Her reading was 443, and her cancer was diagnosed as Stage 4 - near end stage.

But Gavin said Snyder did not accept the diagnosis as a death sentence.

Indeed, Gavin said, Snyder lived far longer than doctors had predicted, probably because she found a vocation in educating others.

"I've heard a number of women tell me that MOCA activities keep them alive," Gavin said.

Also enriching Snyder's life, Gavin said, was the way she intentionally lived each day to the fullest.

"She took a trip a month, to places like California and Italy," Gavin said.

Her Caring Bridge Web site, www.caringbridge.org/mn/raine, included an account of her last trip, to Jekyll Island off the coast of Georgia. The journey included a nine-hour clinic appointment in Jacksonville, Fla.

"I really do appreciate that we are able to take some vacations now," she wrote in her Caring Bridge journal. "It gets a little complicated to coordinate and isn't as much fun for either of us as it would be if I was healthy. But it is still fun.

"This morning when I woke up and was feeling exhausted and in pain and tired of being tired and a little sorry for myself, I thought, 'This is no way to live a life.' And then after remembering I was lucky to be alive, I reconsidered and thought, 'Yes, this is a way to live a life.'"

Husband carries on Snyder's work

Tripp and Raine Snyder had planned to do it together - set up an endowment to educate medical professionals about the symptoms of ovarian cancer.

But, with Raine Snyder's May 4 death, her widower has vowed to carry on the work, along with the "sisterhood" of survivors from the Minnesota Ovarian Cancer Alliance (MOCA).

The Raine Snyder Fund, unveiled at the recent MOCA annual meeting, comes from the Snyders' personal investment, donations, plus memorial gifts given after Raine Snyder's death.

Tripp Snyder said he hopes to grow the fund to \$2 million, and use the interest it generates to create an educational program for physicians.

Although no firm decisions have been made, Tripp Snyder said his initial inclination is to focus the education on gastroenterologists - because they are the specialists most likely to see patients with the symptoms that sometimes indicate ovarian cancer.

"These are the people who patients go to if they have abdominal swelling or diarrhea," he said.

The education program might entail publishing the educational information and hiring an administrator to promote and schedule education sessions.

Tripp Snyder said he'll also be a presence at the Human Resources Professionals annual golf tournament, which was recently named for Raine Snyder. The tournament will be held July 26 at Braemar Golf Course in Edina.

Last year, 100 percent of the tournament's proceeds were donated to MOCA.

He'll also be on hand for an event that was a favorite of Raine's - the Seventh Annual Silent No More Walk/Run for Ovarian Cancer Sept. 16 at Rosland Park in Edina.

"Last year, Raine couldn't do the full event, so I pushed her in her wheelchair," Tripp said - noting that she still raised thousands of dollars in pledges for the fight against ovarian cancer.

"I may even have her empty wheelchair this year," he said.

Ovarian cancer - signs and symptoms

Kathleen Gavin, executive director of Minnesota Alliance for Ovarian Cancer, noted with sadness that the organization often loses its strongest advocates, such as Eden Prairie's Raine Snyder, because ovarian cancer often is not diagnosed in time to save the patient's life.

One of the challenges for health care professionals is that the early symptoms can also be symptoms of any number of conditions.

Symptoms include:

- Bloating, especially around the abdomen.
- Changes in bowel or bladder habits, including persistent diarrhea.
- Excessive fatigue.
- Shortness of breath.
- Weight gain or loss.
- Pain during sexual intercourse.

For a woman experiencing a combination of these symptoms, a blood test called CA-125 should be administered to measure a substance in the blood that may increase when cancer is present.

However, Gavin said, CA-125 should not be administered to all women as part of routine physical examinations. Different women respond differently, and not all women in the early stages of ovarian cancer have a positive result. The test has numerous false positives and false negatives, and conditions such as menstruation, endometriosis, pregnancy or benign ovarian cysts can affect the test results.

Ovarian cancer does not yet have a reliable method of early detection, such as a mammogram for breast cancer or a Pap smear for cervical cancer.

Proteomics is an experimental early-detection tool that screens for a variety of proteins in the blood that might indicate cancer. However, the test is still under study, Gavin said, and no Minnesota hospitals or clinics yet offer it.

Risk factors for ovarian cancer include age (more than half of women who are diagnosed are older than 65); having a family history of ovarian, breast or colon cancer; and not bearing children. A woman should inform her health care provider about a family history of cancer and other risk factors. Yet, many who are diagnosed with ovarian cancer have no known risk factors.

More information is available on the MOCA Web site, www.mnovarian.org.