Young mother lives life under cancer's shadow

Born with a breast-cancer gene mutation, woman faces second battle with deadly disease

BY JODIE SINNEMA, THE EDMONTON JOURNAL FEBRUARY 14, 2009

Lianne cries with her husband Jay at her side as she prepares to go into her sentinel node biopsy surgery at the Cross Cancer Institute.

Photograph by: Candace Elliott, Edmonton Journal

HARD CHOICES

A diagnosis of hereditary breast cancer last October turned Lianne Hanson's life into a struggle for survival, an ordeal she has shared with The Journal's Jodie Sinnema and Candace Elliott. Here is her story.

- TODAY: Finding breast cancer

- SATURDAY: Prevention through mastectomy

- SUNDAY: Part One -- Hope beyond the cancer gene; Part Two -- New nipples from tattoos

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Lianne Hanson thought having cancer on her face would be the worst thing she would have to brave in her lifetime.

A faint scar runs down her right cheek, marking the spot where doctors dug a toonie-sized hole to get

rid of the basal cell carcinoma before it spread.

"Not in a zillion, trillion years" did she think she would find a breast lump at age 31, then be forced to contemplate losing both her breasts and ending her dreams of having a second child, all because the wonky genes she inherited from her mom began to dictate her future.

"It doesn't get any scarier than this," says Hanson, whose life was once governed by irrational fear. Lice were her phobia. Walking in the dark gave her shivers. Swollen glands turned her thoughts to meningitis or the hantavirus, spread by mice. "I didn't want to pass those fears along to my daughter. I've been praying for peace."

Prayer helped her during her Dec. 10, 2007, facial surgery while she held her husband's hand for comfort and rubbed her seven-month-pregnant belly. She had read how some cases end with parts of the nose or lips being cut off.

"It was a dark time in my life. It was painful for me physically and emotionally. I didn't want to walk around with a scar on my face. ... I had no idea of how disfigured I would be afterwards."

The results were promising, and two months later, chubby-cheeked Abigail arrived, lighting up Hanson's life and sweeping away -- at least for a time -- cancer worries.

But two tiny suspicious dots on her face and nose demanded more tests. And while awaiting the biopsy results on the morning of Monday, Sept. 29, Hanson stood by the kitchen window washing Abby's bowl in the sink when she absent-mindedly scratched below her right breast and felt a lump.

"I remember looking up at the sky and saying, 'One thing at a time.' "

Hanson's abnormal face cells ended up being pre-cancerous, treatable with topical ointment. The breast lump ended up being something far worse.

For any woman, finding a breast lump is traumatic and sparks fears of breast cancer, even though 80 per cent of biopsies on foreign lumps turn up benign. For Hanson, finding a breast lump was fate catching up with her far earlier than either she or husband Jason had planned.

When Hanson was 27, she had a genetic test done that confirmed she had inherited the BRCA1 gene mutation from her mother, a rare mutation of the breast cancer gene that ups a woman's chances of getting breast cancer in her lifetime to at least 57 per cent from the usual 12-per-cent risk, with some geneticists elevating that risk closer to 85 per cent. It also puts her risk of getting ovarian cancer at 40 per cent, far higher than the average population's risk of two per cent or less.

Women with BRCA1 or BRCA2 mutations often get those cancers in their 30s or 40s -- sometimes in their 20s -- compared to those with sporadic breast cancer, who typically don't get sick until they're older than 50, although there are exceptions.

Sporadic breast cancer is the most common type of breast cancer. It has no familial link and is caused by a variety of factors.

Hanson, who had a 50-50 chance of inheriting her mother's genetic mutation, wanted her genetic results so she could be proactive about her future. With her positive results, she knew that one day she would likely get a prophylactic oophorectomy, where surgeons would cut out her healthy ovaries to prevent ovarian cancer before it grows. Such a procedure would reduce her risk of breast cancer by up to 50 per cent and the risk of ovarian cancer by up to 95 per cent.

Goodbye painful menstrual periods, Hanson thought positively when the idea was abstract and distant.

And goodbye to the fear that she would die like Nana, her grandmother on her mother's side whose ovarian cancer spread through her entire pelvis over three years, requiring chemotherapy before the invention of anti-nausea drugs, the removal of her bowels and an ostomy, where doctors created an opening in her body to drain waste into a bag.

Nana Mary McDonald's illness and quick decline happened in the late 1980s, when no one knew there was a breast cancer gene and when no hospice care was available beyond visits by the family doctor and priest.

Hanson now knows she was in denial over her personal elevated cancer risk. Even though she and Jason decided they would do everything to keep Hanson healthy, she never considered getting a double mastectomy to help prevent breast cancer.

"I wasn't afraid of breast cancer," says Hanson, still haunted by the childhood moment when she walked by her Nana's door at night and accidentally saw her without her wig. McDonald was diagnosed at 52 and died at 55, living two years longer than doctors envisioned. "It was the ovarian cancer that scared me."

Even so, Hanson likely wouldn't have had the genetic test if she hadn't been in a committed relationship.

"Had I been single or younger, I probably would have been wary," she says. "How do you say to a new boyfriend, 'I'm probably going to get breast cancer and have my breasts and ovaries removed?' "

"Some people are scared of genetic knowledge," says Dr. Dawna Gilchrist, a clinical geneticist who was one of the major founders of the Medical Genetics Clinic. It opened in Edmonton in 1997 and offers genetic tests to women such as Hanson. "It's kind of like looking into a crystal ball or going to someone to have their tea leaves read. They don't want to have any kind of inkling what the future will bring," she says.

Positive test results force women to contemplate preventive mastectomies and oophorectomies that would end the chance to have more children. Some people don't know what to do with the results or feel the knowledge would be a burden to their family, Gilchrist says. Others fear discrimination from insurance companies.

"My gut feeling is that knowledge is power," Gilchrist says. But while she offers patients all the details to make an informed decision on whether or not to proceed with the genetic test, she leaves the decision to them. "It's extremely important, but I accept the fact that not everybody wants to know. The

awareness is a double-edged sword. People who are at high risk should know they're at high risk. People who aren't at high risk should appreciate that they're not."

Of all the women who will get breast cancer, only five to 10 per cent of the cases are due to a single wonky gene inherited from a mother or father.

Of that small group of people who indeed have hereditary breast cancer, only about one-quarter are due to mutations in the BRCA1 or 2 gene, for which there are genetic tests. Doctors know other genetic anomalies exist in other women, who have family histories riddled with breast and ovarian cancers, but geneticists haven't yet been able to find the exact problems, so can't give clear advice on their cancer risk.

Gilchrist says testing is only available for people with a very strong family history that suggests a genetic link. In general, Gilchrist will test a patient with breast cancer if three or more close family members in two or more generations also had breast cancer. That, combined with an early age of cancer onset, is an indication that a gene mutation could be involved.

But calculations are complex: a woman who gets cancer at the age of 22 may just be a hard-luck case. A woman whose three aunts all had breast cancer in their 70s -- an age where cancer is common -- is unlikely to carry the breast cancer gene.

And even if a woman tests negative for the BRCA1 or 2 gene mutations, known to exist in her family, Gilchrist can offer no guarantee she won't get breast cancer. Her risk returns to the average 12 per cent and requires her to get yearly mammograms after the age of 50.

Armed with the knowledge that she carried the known breast cancer gene mutation, Hanson had annual mammograms, as well as blood tests and transvaginal ultrasounds to check for ovarian cancer.

She and Jason also set out a precise plan to have two children before Hanson turned 35, the approximate age by which doctors advise BRCA1-positive women to hunker down and decide on their cancer-fighting plan through preventive surgeries. Jason says they both hoped for a boy, to save a girl from a future of breast and ovarian cancer scares.

Three months after their winter wedding, Hanson got pregnant and the regular cancer checks stopped. At Hanson's first checkup after Abby was born, her obstetrician-gynecologist ordered tests for ovarian cancer, and found nothing abnormal while manually checking Hanson's breasts for lumps.

The doctor said a mammogram was unnecessary, despite Hanson's suggestion to get one.

Hanson didn't push for one, either. She now wishes she had been more assertive and demanded the test be scheduled like clockwork.

"I should have damned well stood up," she says, angst fuelling her newfound activism. "If you are BRCA-positive, you need to take it seriously. It's sad and it's scary, but you have to be ready to start the fighting process."

Instead, luck helped Hanson find her own tumour early and a firm diagnosis came on Oct. 21, 2008. Many tumours don't become physically detectable until they've grown large.

"If someone had supernatural goggles, I would have an army of angels around me," Hanson says, repeating the blessing passed along by her aunt.

As Hanson talks, eight-month-old Abigail rolls, instead of crawls, around their Sherwood Park home. She is obviously adored by both parents. Photos of her are posted on the living room wall underneath a plaque that reads "Courage."

"I had no concept how much I would love being a mom," Hanson says. "It is the most superb thing I have done in my life. I so super want to do it again. Not that Abby is not enough. I just really love the act of being a mother."

Hanson's mother, also named Mary McDonald like Hanson's Nana, found a lump in her right breast in January 2001. She was 41. "I hadn't been doing breast checks," McDonald, 50, says. "I was just living my life."

Less than two months later, McDonald had her right breast cut out, taking the two-centimetre tumour with it.

"This is cancer. My mom died of cancer. I want it off," she remembers thinking. After chemotherapy, an astute oncologist surmised she may have inherited a genetic mutation from her mother and suggested she be tested.

It took three years for the positive results to arrive, since resources for the tests were scarce at the time. McDonald subsequently had her second breast removed, then her reproductive cavity emptied and scraped, sending her into early surgical menopause accompanied by severe hot flashes, anxiety, anger and tears.

Initially -- 10 years after the discovery of the BRCA1 genetic mutation -- McDonald's gynecologist refused to do the hysterectomy and oophorectomy, viewing those operations as an over-reaction to a breast cancer scare. The gynecologist was convinced otherwise when McDonald's mastectomy surgeon, Dr. Kelly Dabbs, known as Edmonton's guru for high-risk breast cancer cases, explained the scientific ramifications of the breast cancer gene.

"It's hard to say goodbye to parts that are still healthy, but after I had it done, I never looked back," McDonald says. "This is what's allowing me to live. One hundred years ago or if I was in a different country, I would be dead and Lianne would be dying with a small baby. I didn't have a mom to go through this with me, but Lianne does."

Hanson's fear is so intense she hasn't touched her tumour since her diagnosis. She has nightmares of female body parts being cut off and imagines the tumour growing inside her while she waits for her first surgery -- a sentinel node biopsy -- that will determine if the cancer has spread to her lymph nodes and potentially other parts of her body.

If that's the case, not only will she need a mastectomy, but a course of radiation would prevent surgeons from reconstructing her breast immediately. Radiation shrinks tissues, restricts blood flow and causes the body to lay down scars.

"I'm really scared," says Hanson, fiercely gripping Jason's hand just before being wheeled into the operating room Nov. 5, 2008. "This is happening way faster than I thought."

At one point, she stares at a photo of her daughter, and chants to calm herself: "Abby. Abby. Abby. Abby. Abby."

After Hanson is anesthetized, Dabbs begins cutting into her right armpit, searching for the sentinel node. It is the guardian of the armpit, the first in a long line of lymph nodes that are ripe with white blood cells. As fluid leaves the breast to circulate through the body, it drains into the lymph nodes, which attempt to fight any infection or cancer trying to escape and travel. If Hanson's breast cancer has spread, diseased cells will be trapped in the sentinel node.

Dabbs's fingers dig deep, searching for lymph nodes that are like chains of grapes, but very difficult to see. To help, a radioactive agent was injected into Hanson's breast the day before and circulates through the breast and lymph nodes. The sentinel node traps the radiation as it would cancer, so when Dabbs cuts it out and holds it to a probe attached to a gamma counter, it beeps wildly.

This tiny node is immediately sent down the hallway to the pathology lab where Dr. Richard Berendt cuts it up and puts it under a microscope in search of cancer cells. Minutes later, he tells Dabbs: "I don't see any tumour there."

The cancer hasn't spread, Dabbs tells a groggy Hanson as she wakens from surgery.

"Praise Jesus," Hanson says.

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VITAL STATISTICS

BREAST CANCER

The average woman has a 12-per-cent chance of getting breast cancer by the age of 70.

A woman with the BRCA1 genetic mutation has a 57-per-cent chance of getting breast cancer by 70, meaning her risk is five times higher than the average woman. Until quite recently, the risk was pegged at 85 per cent, when especially susceptible families were first found and rather easily identified since they had an incredibly high number of cancer cases. As less susceptible families are being identified, the risk is being lowered.

A woman with the BRCA2 genetic mutation has a 49-per-cent chance of getting breast cancer, meaning her risk is four times higher.

OVARIAN CANCER

The average woman has a 1.5- to two-per-cent chance of getting ovarian cancer by the age of 70.

A woman with the BRCA1 genetic mutation has a 40-per-cent chance of getting ovarian cancer by 70, meaning her risk is 20 to 25 times higher. The risk was formerly pegged at 50 per cent, but is decreasing as more families are being identified.

A woman who is BRCA2 positive has an 18-per-cent chance of getting ovarian cancer, meaning her risk is nine times higher.

Men with BRCA1/2 mutations (particularly BRCA2) face a higher lifetime risk for prostate cancer (20 to 25 per cent compared to five to 10 per cent in the general population).

BREAST CANCER FACTS:

Sporadic breast cancer is the most common type of cancer among Canadian women.

IN 2008:

- An estimated 22,400 women in Canada were diagnosed with breast cancer. That's about 431 each week.

- An estimated 170 men in Canada were diagnosed with breast cancer.

- An estimated 5,300 women and 50 men died from breast cancer.

One in every 28 Canadian women die from breast cancer. Two-thirds of those diagnosed will live through it.

Source: Canadian Cancer Society

SPORADIC VERSUS HEREDITARY BREAST CANCER:

- Of all women who get breast cancer, 90 to 95 per cent get sporadic breast cancer, which is caused by a grab bag of factors, some that might be unexplained, others that might be linked to age, personal habits (smoking) or medications (such as hormone replacement therapy).

- Five to 10 per cent of women get hereditary breast cancer, where they have inherited a wonky gene from their mother or father that dramatically increases their risk of breast or ovarian cancer.

- BRCA1 and BRCA2 gene mutations -- the only known and identifiable breast cancer genes -- account for 20 to 25 per cent of this small hereditary sub-group. That means genetic tests, which can only find the BRCA mutations, only cover about one to two per cent of the population.

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To learn more about mammograms and breast health, listen to Screen Test's Joan Huber at edmontonjournal.com/videos.

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Lianne cries with her husband Jay at her side as she prepares to go into her sentinel node biopsy surgery at the Cross Cancer Institute.

Photograph by: Candace Elliott, Edmonton Journal