



Maureen's MISSION

Saving Women's Lives Through Education

554 Oberdorfer Road
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About Maureen's Mission

Not long before Maureen Thiel died of breast cancer at age 43, she called her husband, Bill, into the bedroom.

"Sit down on the bed," she said. "I want to talk to you about something."

Bill sat down.

"I want you to promise me you'll do three things after I'm gone."

"Anything, honey," Bill replied. "Whatever you want."

She told Bill she wanted him to love their two sons, Erik and Ryan, twice as much because she wouldn't be there to love them anymore. She asked him to promise her that he would love again, that he wouldn't spend the rest of his life alone. Bill said he would, even though he didn't feel he ever could.

And, finally, she asked Bill to "tell my story" so that other women wouldn't suffer the same horrible fate.

Maureen Thiel didn't want her life – or death – to be in vain.

The Mission

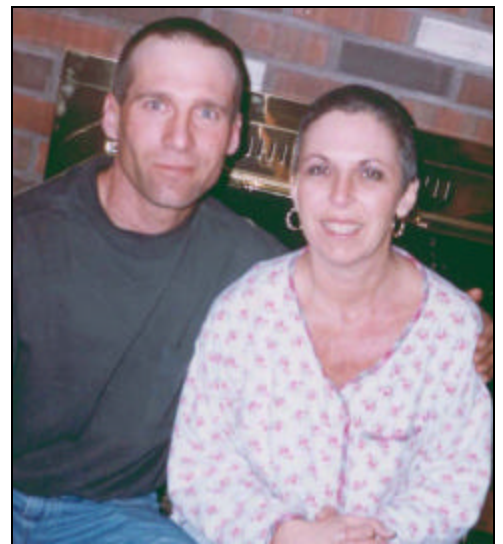
Today, Bill Thiel is carrying out his wife's dying wish by starting Maureen's Mission, a non-profit organization dedicated to educating women with breast cancer and advocating for changes in the system that will save other women's lives.

Through his experience with Maureen's case, Bill has identified two critical action areas where systemic change and increased education are badly needed – a Universal Standard of Care for the diagnosis, treatment and follow-up of breast lumps, and giving women the legal right to demand a biopsy.

"Before this happened to Maureen, I didn't know anything about standard of care, but Maureen and I both became experts fast," says Bill. "Maureen had been taught to self-examine back in high school and that's how she found the first lump in her breast. Unfortunately, that's where her knowledge ended. She had never been educated about what happens next – about standard of care. Most women don't know what it is and the truth is, a lot of doctors don't even know what it is."

Standard of Care

Accepted standard of care for the diagnosis, treatment and follow-up of breast lumps requires that once a lump is found, either a biopsy is performed immediately to determine if it is cancerous, or the patient is ordered to return for a follow-up visit within 30 days during a different part of her menstrual cycle. If, upon second examination, the lump still appears suspicious, a biopsy must be performed. The test can be as simple as inserting a needle into the lump and drawing fluid for testing.



BY HER SIDE: When Maureen, a beautician, started losing her hair after chemotherapy, she was devastated. She had decided beforehand that when it started happening, she would shave her head. As soon as Bill finished shaving her head, he shaved his own. About 30 of the Thiels' friends and neighbors did the same to show support for Maureen.

No Standard for Standard of Care

The problem with standard of care is that it is anything but standard. What is considered the “standard” in one community might not be the standard in another, and doctors are not legally required to follow it, whatever the standard might be. There is no uniformity in standard of care.

Universal Standard of Care Needed

For the safety of women everywhere, we need a Universal Standard of Care that specifies how breast lumps are diagnosed and treated in every community across the United States. Maureen’s Mission will be working with state legislators and members of Congress to 1) establish a Universal Standard of Care for the diagnosis, treatment and follow-up of breast lumps; 2) require doctors and other health-care providers to follow it; and 3) educate women about it through a government-funded public relations program.

The Importance of a Biopsy

In Maureen’s case, three different doctors on three different occasions over 18 months misdiagnosed her



MUSTERING THE STRENGTH TO FIGHT:

Maureen went through numerous courses of increasingly aggressive chemotherapy, stem-cell replacement therapy and surgeries. “She was a fighter,” says Bill. “I could have never fought as hard as Maureen.”

breast lumps as non-cancerous fibroid cysts because they never performed a biopsy to rule out cancer. The only diagnostic tools they used were mammograms and ultrasounds, but neither one of those methods can determine whether a breast lump is cancerous. Maureen was at the mercy of her doctors and health-insurance provider. Because she was always deathly afraid of getting breast cancer,

and was troubled by the lump in her breast, Maureen would have exercised her legal right to a biopsy, if she had had one. If a biopsy had been performed earlier, Maureen might still be alive today.

It’s a No Brainer: Women Should Have the Right

Maureen’s Mission will lobby state and federal legislators to pass a law that will 1) give women the legal right to demand a biopsy of a breast lump and 2) educate women about their legal rights through a government-funded public relations program.

Saving Lives

Establishing a legally binding Universal Standard of Care for breast lumps and granting women the right to demand a biopsy could save hundreds, perhaps thousands, of lives every year in the United States. The horrible truth is that, as you are reading this, somewhere a woman is being sent home with a lump in her breast. She is being told what Maureen was told: “Don’t worry. It’s not cancer. Come back in a year for your annual mammogram.”



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Maureen's Story

Maureen and Bill Thiel were an average, working-class American couple. He was a landscaper. She worked as a beautician part-time at home where she could look after her two young sons.

The love they shared was something really special, the kind of love that only happens in movies or storybooks. On their first date, Bill says, he realized he was looking at his future wife. After their second date, they moved in together and never parted. When his co-workers wanted Bill to go have a beer after work, Bill always wanted to go home to Maureen. "The best gift anyone ever got times 20 million isn't a gift like I got," says Bill.

Eventually, they had two sons, Erik and Ryan, and moved to the Poconos where they became active in their church and well-loved in their community of Bushkill. They enjoyed camping and cookouts, doing everything together as a family. "Whenever we wanted to do something with the boys, it was always a picnic basket and a state park," says Bill.

Maureen Finds a Lump

In November 1994, Maureen found a small lump in her left breast while performing a self-examination in the shower. After an exam, mammogram and ultrasound by her family doctor, Maureen was told it was a non-cancerous fibroid cyst and that she should come back in a year for her annual mammogram. Six months later, in May 1995, the lump was bothering Maureen even more, so she made an appointment with a different doctor – a woman from the same medical group. Maureen had hoped perhaps

a woman doctor might be more aggressive

in determining whether the lump was cancerous. During that exam, the doctor found a second lump but concurred with the earlier diagnosis that the lumps were benign cysts. Maureen was told to come back in November 1995 for her annual mammogram.

"Maureen came home and she was happy," says Bill. "There was nothing to worry about."

When she returned to the doctor in November 1995, her mammogram revealed two "masses," but the doctor – the same one who had examined Maureen six months earlier – said it only confirmed the earlier diagnosis of fibroid cysts. By this



SOUL MATES: On their first date, Bill says he knew he was looking at his future wife. After their second date, Bill packed up his apartment and moved in with Maureen. They never parted.

'Take me to Wal Mart'

A month before Maureen died, she was home briefly and asked Bill to take her to the funeral home so she could pick out a casket and plan her service. On the way, they passed Wal Mart.

Maureen loved Wal Mart and she hadn't been there in a long time. "I want to go to Wal Mart," she told Bill. "Take me to Wal Mart."

When they parked the car, Maureen told Bill she was having trouble breathing and couldn't feel her legs. He suggested they get to the hospital right away. No, she said, she wanted to go to Wal Mart. Bill pulled the car up to the front of the store and got a wheelchair from inside for Maureen.

When they got in the store, she told Bill to take her to the jewelry department. There, she bought her husband a \$79 wedding band. Bill, a landscaper, had broken his ring at work. Maureen wanted him to have a new one before she died.

time, the cysts were painful and bothering Maureen. Bill says he could no longer hold Maureen like he always did in bed because of the pain it caused her. Six months later, in May 1996, she returned to the same doctor, complaining of pain radiating down her arm from the lumps, and demanded to consult with a surgeon to have them removed. When she saw the surgeon the same month, he told her she had too many lumps to have them removed, that he would have to remove her entire breast. But, he said, "You don't have cancer," and assured Maureen that such cysts were common in women her age.

The Thiels went on living their lives as though nothing was wrong.

Late in 1996, Maureen found a lump in her armpit about the size of a pea. Because the Thiels had just changed health insurers, Maureen went to a different doctor who immediately ordered a biopsy. During the biopsy in March 1997, Bill remembers sitting in the quiet waiting room of the outpatient surgery center at Newton (N.J.) Memorial Hospital when he heard the scream.



ALL DRESSED UP: Bill and Maureen ready to paint the town in their finest attire.

The Scream

"The scream engulfed everything," Bill says. "It came lashing down the hall like an electric charge. It filled each space it found and jolted every nerve. We all turned to it; we couldn't help it. The scream controlled us as it rose and expanded into layers of screams. It was the scream you'd make if your hand was cut off. The scream you'd make if your child was run over. The scream of being raped. It was like nothing I'd ever heard before. I looked for the ambulance, for the flashing lights, for the stretcher all bloody. I looked for the emergency room. But the scream came toward me and it was calling my name." [Excerpted from book being written by Maureen Buchanan Jones. Copyright © protected.]

As Maureen was wheeled by on a gurney, she was screaming, "Bill! Bill! It's cancer!" The surgeon had biopsied 47 different lymph nodes from Maureen's armpit and found cancer in every one. Bill was told she

had two years to live, but didn't tell Maureen because he knew she had to stay positive. "Her lymph nodes were reproducing so fast trying to fight the cancer, they were like bunches of grapes," Bill says.

Within days, unbeknownst to Bill, Maureen drove herself to Scranton and retained the Foley Law Firm to represent her in a malpractice lawsuit against the doctors who had failed to diagnose her cancer.

Treatment Begins

That week, Maureen underwent a lumpectomy to remove the cancer from her breast and started chemotherapy. Between March 1997 and May 1998, when Maureen finally died, Bill couldn't work because Maureen required daily doctor visits and constant care. "It drained us financially," he says. "We lost everything."

The first round of chemo seemed to go well, but during a camping trip in June 1997, Maureen called her husband, "Bill, come here."

"Maureen had two different ways of saying, 'Bill, come here,'" Bill recalls. "One was a nice way, like she wanted to tell you something or show you something in the yard. But the other one, when you heard it, you didn't walk – you ran. This was one of those."

'A REAL TROOPER':

No matter how sick she was, Maureen tried to attend the kids' functions and keep living her life as normally as possible. "Maureen was a real trooper," says Bill. "I don't know where she found the strength. I would have just laid down and died."



'Our last New Year's Eve'

After her stem-cell replacement therapy in the fall of 1997, Maureen was home for Christmas. She and Bill had planned to take the boys to see the opening of the movie "Titanic" on New Year's Eve, but that morning, she had discovered her tumor growing again. Rather than go to the hospital, Maureen wanted to go to the movies, as planned.

When the movie was over, confetti and balloons streamed down from the ceiling, welcoming the new year. Bill and Maureen just held each other and cried.

"The boys thought we were crying because we were happy," says Bill. "But we were crying because we knew that would be our last New Year's Eve together."



FIGHTING AGAINST THE ODDS: Maureen went through numerous courses of increasingly aggressive chemotherapy, stem-cell replacement therapy and surgeries.

A touching good-bye

On the day before Maureen died, the Thiels' best friends, John and Helen, stopped by the house. Helen had made two patchwork quilts -- one for each of the boys. On each of the quilts, there were five squares symbolizing the things Maureen loved -- scissors (she was a beautician); a campfire (the two families loved to go camping together); a Christmas tree (Maureen loved Christmas); angels (Maureen collected them); and two children (the boys). A sixth square was left blank.

With tears streaming down her face, Helen covered Maureen's palm with paint, then pressed it against the blank squares, completing each of the quilts with Maureen's handprint.

"That was Helen's way of saying good-bye," says Bill.

Maureen's left arm was inflamed. The tumor had started growing again -- fast. Maureen started a more aggressive course of chemo, but the tumor kept coming back. Meanwhile, she had consulted with another oncologist, who suggested she consider experimental stem-cell replacement therapy. By the time Maureen had her first visit with the New Jersey doctor who would oversee her stem-cell therapy, her left breast was "hard like a softball," Bill says.

Stem-Cell Replacement Therapy

Stem-cell replacement therapy required Maureen and Bill to be quarantined in the hospital for weeks. Maureen had to take massive doses of chemotherapy that nearly killed her and left her with no immune system. The course of treatment ended in November 1997 and Maureen came home for Christmas. Her breast felt soft again, normal. The plan was to wait six months until her immune system recovered and perform a mastectomy to remove the breast. On New Year's Eve, she and Bill had planned to take the boys to see the debut of the movie, "Titanic." That morning, Bill heard those awful words, "Bill, come here."

She could feel the tumor coming back. She wanted to go to the movies anyway.

The next day, Maureen underwent an emergency radical mastectomy of the left breast. Within a week, surgeons removed her right breast because the cancer had spread. In February, Maureen was back home recuperating when she developed a bad headache. The cancer had spread to her brain and bones. By the end of March 1998, it was in her lungs. In April, during a brief stay at home, Maureen made Bill take her to the funeral home so she could pick out a casket and urn, and plan her funeral service. She didn't want to put Bill through that. She was having trouble breathing and could barely walk. The next day, she was back in the hospital.

In May, Bill brought her home for the last time -- to die in the sunroom he had built for her. Maureen had always wanted a sunroom and Bill found the time -- sometimes going for weeks without sleep -- to build it for her. Four days later, on May 16, 1998, she died. "Me and the boys, we didn't cry," says Bill. "We had cried so much already, our tears would have filled buckets. In the end, Maureen was in so much pain, we were happy when she finally died -- happy that her suffering was over."

'Everywhere You Went, It Was Just Pain'

After Maureen died, Bill says he and the boys had to move away from their beloved home in Bushkill because the painful reminders of Maureen were everywhere. "Maureen's death just devastated everybody," Bill says. "People couldn't even look me in the eye anymore because it just hurt so much. Everywhere you went, it was just pain."

Epilogue - Posthumous Justice

In the summer of 2004, more than six years after Maureen's death, her malpractice case went to trial. She had sued her doctors, not because she wanted money, but because she felt betrayed and wanted to hold them accountable for failing her. Perhaps more important, she hoped her case would somehow change the system and save other women's lives. After hearing extensive testimony in the case, a jury in Monroe County Court awarded \$5.4 million in damages -- the largest malpractice verdict in the county's history.

"I talked to some of the jurors after the trial," Bill says. "They couldn't even talk about it. They were so devastated by what they heard in the courtroom. The one guy asked me to call him back in a year. He told me he had been walking around in circles, that he couldn't sleep, couldn't eat, couldn't think about anything else. Everybody who hears Maureen's story is just devastated by it."



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How the Lack of a Universal Standard of Care Contributed to Maureen Thiel's Death

- 1) Three different doctors examined Maureen's breast lump, but none followed accepted standard of care.**
- 2) Maureen's doctors failed to rule out breast cancer through biopsy, as prescribed by accepted standard of care for the diagnosis, treatment and follow-up of breast lumps.**
- 3) Maureen had a persistent breast lump that went undiagnosed from November 1994 until May 1996, despite repeated visits to different doctors.**
- 4) After her first examination, Maureen was not brought back for a second exam within 30 days – at a different time in her menstrual cycle – as prescribed by accepted standard of care.**
- 5) Maureen did not get adequate follow-up care from her doctors.**
- 6) If her doctors had performed a biopsy soon after Maureen first found her breast lump, there's a good chance she would still be alive today.**



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STANDARD OF CARE

For the Diagnosis, Treatment and Follow-Up of Breast Lumps

<u>What We Have Now</u> (With No Universal Standard of Care)	<u>What We Should Have</u> (With a Universal Standard of Care)
A Silent and Deadly Epidemic of Misdiagnosis	Comprehensive and Uniform System of Diagnosis That Will Eliminate Misdiagnosis and Save Lives
Some Doctors Applying Different Standards of Care	All Doctors Applying the Same Standard of Care to All Patients
Some Doctors Treating Lumps as Benign Until Proven Cancerous	All Doctors Treating Lumps as Cancerous Until Proven Benign
Some Breast Cancer Diagnosed Early	All Breast Cancer Diagnosed Early
Increased Risk of Cancer Spreading	Reduced Risk of Cancer Spreading
Patients Ignorant About Standard of Care	Patients Educated About Standard of Care and Made Partners in Diagnosis and Treatment
Broken Trust and Hostility Between Patients and Doctors	Bond of Trust Restored Between Patients and Doctors
Acceptance of Misdiagnosis	Rejection of Misdiagnosis, Increased Accuracy and Effectiveness in Medical Practice
Higher Risk of Litigation	Lower Risk of Litigation
Higher Health Care Costs	Lower Health Care Costs
Compromised Patient Safety	Comprehensive Patient Safety
Families and Communities Devastated by Tragedy	Healthy Families and Communities



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Universal Standard of Care

For the Diagnosis, Treatment and Follow-Up of a Breast Lump

- 1) **Standard of Care will be the same throughout the United States.**
- 2) **All lumps will be treated as cancerous until proven otherwise.**
- 3) **If a lump is found, either by self-exam or clinical exam, patient receives a pamphlet outlining Standard of Care and the steps the patient and doctor will follow together to provide an early diagnosis.**
- 4) **Mammogram or ultrasound, or both, performed immediately.**
- 5) **Biopsy will be discussed and patient will be given a choice, after consultation with the doctor, to proceed with biopsy.**
- 6) **If, after consultation with doctor, patient decides to wait for biopsy, only one menstrual cycle will be allowed to pass before patient returns for re-evaluation of the breast lump.**
- 7) **If breast lump persists, biopsy immediately.**
- 8) **In all cases, early diagnosis will be sought to maximize patient safety.**



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“Evaluation of Common Breast Problems: Guidance for Primary Care Providers”

CAA Cancer Journal for Clinicians, Vol. 48, No 1, January 1998

Excerpts

- "A normal mammogram at any age does not eliminate the need for further evaluation of a palpable suspicious mass."
- "The workup of a patient with a solid, dominant mass (suspicious mass) should include a bilateral mammogram and may also include ultrasonography or aspiration. In this situation, the primary purpose of the mammogram is to screen the normal surrounding breast tissue and the opposite breast for non-palpable cancers, **not to make a diagnosis of the palpable mass.**"
- "Ultrasonography is contraindicated for routine breast cancer screening because of its inability to depict microcalcifications."
- "The ultimate complete pathologic assessment of a breast lesion is open surgical excisional biopsy, or lumpectomy."
- "Fine-needle aspiration for cytologic analysis is extremely useful as an adjunct to clinical evaluation of a palpable mass. Fine-needle aspiration can diagnose and eliminate a fluid-filled cyst or aspirate tissue for cytologic evaluation of a solid mass."
- "Any mass remaining after aspiration of a cyst should be excised. Negative findings of fine-needle aspiration in the presence of a suspicious mass mean nothing and should not preclude further diagnostic biopsy."

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