



MELISSA'S LAW FOR FERTILITY PRESERVATION

Connecticut's landmark legislation opens access to fertility treatment



On June 20, 2017, Connecticut Gov. Dannel Malloy signed and enacted Melissa's Law for Fertility Preservation, ensuring that individuals diagnosed with cancer do not have to choose between their lives and their reproductive futures. The landmark legislation made Connecticut the first state in the country to require coverage for fertility preservation based on medical necessity.

Patient advocate Melissa Thompson was a catalyst to the bill's passage. Her personal battle with Stage III breast cancer at the age of 32 fueled her passionate work to change the law for future cancer survivors.

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A Devastating Diagnosis

Just five weeks after giving birth to her daughter, Poppy, Thompson received the devastating news that she had cancer. She described her delivery at Greenwich Hospital as normal, but when she began having persistent, high fevers, she knew something was amiss. Thompson was originally diagnosed with mastitis, a breast tissue infection frequently caused by clogged milk ducts in breastfeeding mothers.

Two courses of antibiotics did not alleviate her fevers. Sick and exhausted, she was sent to see a breast surgeon, who told her she likely had an abscess, but ordered a biopsy to be certain. Shortly thereafter, Thompson received the results. It was cancer.

“During the first few weeks of a cancer diagnosis, there is a lot of anxiety while waiting for test results,” said Thompson, who fell into a rare category of pregnancy-associated breast cancer. She needed a double mastectomy to remove seven centimeters of tumors.

During an initial appointment, her breast surgeon recommended that she see a fertility specialist. Thompson was grateful for the advice, as patients are often not informed that chemotherapy can cause infertility. According to the American Cancer Society, only 13 percent of cancer patients are educated about their fertility options.

“This was psychologically difficult as a brand new mom,” said Thompson. “I was learning to juggle being a mom with feeling sick and discovering I had cancer. The joy of new life and the fear of mortality were two concepts that did not mix.”

The timeframe is limited between diagnosis and starting treatment with surgery and chemotherapy. This meant Thompson needed to decide quickly if she wanted to freeze her eggs and preserve her chance to have more children. Thompson's insurance company preauthorized the procedure. “The fertility treatment process took 16 days. I had egg retrieval on a Friday and a double mastectomy the following Monday,” she said.

Two days before her egg retrieval, Thompson's insurance authorization was reversed on the grounds that she had cancer, not infertility. Having already gone through two weeks of giving herself hormone injections, and breast surgery set for the following week, she went through with

the egg retrieval, charging the \$12,000 procedure on her credit card. “I went into this with the understanding the procedure was covered, but if I was presented with the choice of spending \$12,000 on it, it would have been a difficult decision to make,” said Thompson.

Following surgery, an aggressive course of chemotherapy caused Thompson to spend several weeks in the hospital. When she finally got home and started to feel better, she opened her mail to discover that her insurance appeal window had closed. “Many cancer patients don't appeal insurance decisions because they are too sick to fight and end up going into medical debt. I appealed the reversal, but the insurance company kept denying it,” she said.

Thompson reached out to state Rep. Caroline Simmons of Stamford at the suggestion of the Oncofertility Consortium at Northwestern University, which she first called for help with her appeal. “Caroline was so wonderful,” she said. “She personally wrote a letter to my insurance company and put me in touch with the Connecticut Insurance Department and the Connecticut State Office of Healthcare Advocacy.”

“I was fortunate to get to know Melissa Thompson when she lived in my district in Stamford and to learn about her incredible story of bravery and perseverance,” said Simmons. “Melissa has devoted herself to passionately advocating for insurance coverage for fertility preservation, so that other women do not have to experience the uncertainty and pain that she went through.”

Passing the Bill

The Connecticut Insurance Department, which regulates the insurance industry in the state, told Thompson that her insurer was correct in that she was not covered for fertility preservation. Based on this decision, the Office of Healthcare Advocacy was unable to do anything further to help with her case.

“It felt really wrong,” she said. “They were effectively saying, ‘We know you're going to have treatment that causes infertility, and you'll be covered for in vitro fertilization once you're infertile.’ Preserving fertility beforehand just seemed like a much more logical option.”

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Thompson explained that many cancer survivors go through with IVF after their cancer treatment, despite low probabilities of achieving and maintaining a successful pregnancy. It made no sense to her from either a moral or financial perspective. After doing some research, she discovered that legislation regarding this issue was previously introduced, but never passed.

Thompson thoroughly reviewed what had already been written and knew she needed to present a stronger case that could pass a financial analysis. In past legislation, everyone under the age of 65 was included in the budget, which accounted for over a third of the population who wouldn't even be candidates for fertility preservation.

Without representation by a lobbyist or legislator, Thompson attended an insurance committee hearing in Hartford. "I went up to a lobbyist for the insurance companies and asked her what it would take to support a bill for fertility preservation for cancer patients. She told me that everyone presents their arguments by saying it will save money in the long run, but no one really has proof to back that up."

Research and preparation eventually paid off. Thompson went to another hearing with 30 copies of her well-documented, 82-page report. It addressed the budgetary inaccuracies of past bills as well as guidelines from medical associations recommending that cancer patients be educated on their fertility and the consequences of treatment.

She also figured it would end up saving insurers 27 percent over three years, and pointed out an improved quality of life that could not be quantified. "As the insurance committee in Hartford, which is nicknamed the 'insurance capitol of



Thompson and Lesser celebrate after the bill is passed by the Connecticut State House of Representatives.

the world,' they had the responsibility to set framework for insurance companies that allows them to do the right thing structurally for the long term, and not necessarily answer to their shareholders of the day," she said.

She pointed out that young people often have unsteady financial circumstances, making it difficult for them to opt for fertility preservation if it were not covered by insurance. "Their futures are then foreclosed," she said. "It is hard to ask a person to make a decision to pay a \$12,000 medical bill when they don't have the finances to even consider something at that high of an expense. More than 60 percent of Americans cannot come up with \$1,000 in an emergency. It's just not an option."

Thompson's testimony stuck with the lawmakers, who cited her research and added points that made her argument even stronger. State Rep. Jonathan Steinberg of Westport noted that in an effort to preserve their chances of having a child, women with cancer may avoid or seek alternatives to chemotherapy, thus risking their lives.

During her quest to pass the legislation, Thompson received countless messages from fellow cancer survivors. She recalls one that said, "I have a hole in my heart that will never be filled, and wouldn't wish it on anyone."

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“Everyone understood why this was important and that it was something they should do. That’s why they’re our representatives, to change policy and do the right thing for people. To have it pass unanimously was incredible.”

Thompson’s hope is that no one will ever have to utter those words again.

Despite many obstacles, including a missed committee hearing deadline and an attempt to include the proposed legislation in an omnibus bill that was unlikely to pass, Thompson persevered. She is grateful to a number of people who helped her throughout her journey. State Rep. Matthew Lesser from Middletown, a fellow cancer survivor, championed the bill from early on.

“I introduced this legislation for four years, but what changed this year was the extraordinary impact of Melissa’s advocacy, which shows the power that one individual can have,” said Lesser. As a result, Connecticut now leads the country by expanding coverage and ensuring that young people with cancer diagnoses can get the fertility coverage they need.”

“Something I didn’t realize that I wish more people would, is that our representatives are accessible people and they’re really helpful,” said Thompson. “Anyone in the state can walk into the Capitol building. Anyone can go to a public hearing, speak at a public hearing, contact their representative and ask for something, or put in a grievance or concern.”

On June 2, 2017, the Connecticut Senate unanimously passed HB 7124, Melissa’s Bill for Fertility Preservation. Thompson was given the privilege of standing behind the dais with Lt. Gov. Nancy Wyman and gaveling the bill’s passage. The bill previously passed the Connecticut State House of Representatives 148-0.

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Melissa with her daughter, Poppy

The new law amends the existing insurance requirement for infertility coverage in the state by changing the definition of infertility. Previously, it was defined as “the condition of a presumably healthy individual, who is unable to conceive or produce conception or sustain a successful pregnancy during a one-year period.” The new law removes the words “presumably healthy” from the definition, and extends it to include those for whom fertility services are “medically necessary.”

“This was a bipartisan bill, and both a pro-life and pro-choice bill,” said Thompson. “The No. 1 American value is family, and this bill was very pro-family.”

At a Women in Government conference Thompson recently attended, 13 states asked if they could introduce her bill in their next legislative sessions. It has already passed in Rhode Island. “My goal is to get this passed in all 50 states and address it at the federal level,” she said. “No one should be forced to make the agonizing choice I faced after my cancer diagnosis – the choice to compromise either my survival or the ability to have a family in the future. Thanks to this bill, those diagnosed with cancer can focus on saving their own lives, while not precluding their future families.”

Today, Thompson is working on writing a book about the power of the patient voice in the future of healthcare systems and the delivery of care. “Throughout my journey, I learned that if you feel something is wrong, you need to stand up for it. If it’s unjust, there are people who can make it right,” she said. “I don’t want to just help myself. I want things to change for the right reasons.” ■