



February 5, 2021

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The Honorable Representative Joel Ferry  
Chairman, House Business & Labor Committee  
Utah State Legislature  
350 North State Street  
Salt Lake City, UT 84114

**RE: Support for HB 192**

Dear Representative Ferry:

On behalf of the Alliance for Fertility Preservation (the AFP), we are writing to express our support for House Bill 192 which would require certain health insurers to provide coverage for standard fertility preservation services when a medically necessary treatment such as chemotherapy or radiation may directly or indirectly cause iatrogenic infertility.

We are a national 501(c)(3) organization dedicated to expanding fertility resources for cancer patients and survivors. We have deep professional experience with this patient need, and we know that due to advances in reproductive technology, cancer need not preclude parenthood. Offering techniques to preserve fertility is now recognized by all relevant medical societies as a standard part of cancer care, but access remains a challenge.

Based on the Utah State Cancer Registry, annually, more than 1000 Utahns are diagnosed with cancer while still in their reproductive years (under age 45). Despite the high likelihood (better than 80%) that they will survive their cancer, these patients may involuntarily lose an important part of life after cancer – having a family.

HB 192 would help alleviate this unnecessary loss by allowing patients the realistic opportunity to safeguard their genetic material prior to beginning possibly sterilizing chemotherapy, radiation, or surgery for cancer. Without insurance coverage for these services most patients simply cannot afford preservation measures.

For these reasons, we respectfully ask that you pass HB 192.

Sincerely,

A handwritten signature in cursive script that reads "Joyce Reinecke".

Joyce Reinecke,  
Executive Director

Hi, my name is Brittany Watkins, I am 26 years old.

I am currently going through Immunotherapy treatments. I was diagnosed on the 31<sup>st</sup> of March 2020 with a rare form of Melanoma Cancer. After I had surgery to remove the cancerous mole and the lymph nodes that had been affected by cancer in May 2020. I went to see my oncologist Dr. Kenneth Grossmann, and was told that if I wanted my own biological children that I needed to do the egg retrieval and preservation before starting Immunotherapy asap, because there are not many case studies to show how Immunotherapy responds to the reproductive system. I am currently insured through my parent's insurance and they won't cover fertility for cancer patients, so I had to come up with getting the money on my own, which was highly stressful and extremely expensive, and time consuming which put my life in jeopardy for me and my family. Going through cancer at such a young age is a challenge in and of itself, but to hear that my chances of having my own children could be ruined because of Immunotherapy is like a punch to the stomach as well as to the heart. All I've ever wanted to be, since I was a little girl, was to be a mom to my own biological children, To carry my own children in my womb and eventually in my arms has been a lifelong dream. Now all that is in jeopardy because of me having cancer and going through Immunotherapy.

It's been said that covering fertility cost for cancer patients is a luxury. If you ask anyone who has struggled with fertility, like my parents have. They will tell you it is the furthest thing from a luxury. This is my life I am dealing with now since being diagnosed with cancer. No one asks to have cancer, let alone fertility problems. I never asked or even wanted cancer in the first place I have seen what cancer does to a loved one. I watched my grandma die from the same type I have, But now the insurance companies believe that fertility for all people is a luxury, I am being denied my rights to be able to have my own children because they refuse to cover fertility because they believe it's a luxury to them.

The International Conference of Population and Development Program of Action states that, "reproductive health... implies that people are able to have a satisfying and safe sex and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so. Implicit in this last condition are the rights of men and women to be informed and to have access to safe, effective, affordable, and acceptable methods of family planning of their choice, as well as other methods of family planning of their choice for regulation of fertility which are not against the law and the right of access to appropriate healthcare services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant..." (Quoted by the World Health Organization)

Going through cancer is already a financial struggle, even with insurance. Now all my hopes and dreams are at risk if I, alone, am unable to come up with the funds to continue paying for the storage fee to freeze my eggs until the time comes for me to start having children which I have to wait for 5 years or get a surrogate, I have to be 5 years cancer free. It is a constant stress for me, I suffer from anxiety and going through cancer and fertility plus try to manage everything in my life is a struggle. The lives of my future children are,

as of right now, undecided because of such a heavy financial burden. My family has done their best to help me, as far as raising the money by doing fundraisers, etc. But there is only so much they can do with everything else they have to do, its stressful and taxing for them as my parents as well as me. My dad is currently trying to appeal the whole fertility process with his insurance. Life, especially these days, is unsure for many of us. Will you please consider in the future helping other patients suffering from cancer to fulfill their hearts desires to have a family of their own.

Sincerely,

Brittany Watkins and Family

## Fertility Preservation Coverage – Key Points

### Purpose

The purpose of legislation for fertility preservation coverage is to provide cancer patients access to standard medical treatments that will protect their capacity to have biological children.

### Background

In the United States, approximately 160,000 individuals between ages 0-45 are diagnosed with cancer each year.<sup>1</sup> As cancer survivorship improves, these patients face good odds; approximately 80% will survive.<sup>2</sup> The treatments that are required to treat the cancer can directly or indirectly cause medically-induced (iatrogenic) infertility. Chemotherapy, radiation, and surgery can damage gametes (eggs and sperm), reproductive organs, and/or endocrine functioning; they may also impact the ability to carry a pregnancy. Because this damage is caused by treatments and not the disease, it can affect patients with any type of cancer. Patients with other conditions requiring similar therapies (e.g., sickle cell anemia, lupus, and thalassemia, etc.) are also at risk.<sup>3</sup>

### Costs

Cost is often cited as the most significant barrier to fertility preservation.<sup>4</sup> Costs can range from several hundred dollars for sperm banking, to approximately \$15,000.00 for egg banking.<sup>5</sup> Without insurance coverage, these treatments are unaffordable for many patients. These costs are exacerbated by the short window of opportunity that cancer patients have before starting potentially-sterilizing cancer treatment. While the costs faced by an individual patient are high, the cost of implementing coverage across a population of insureds is very low. Independent analyses in states where coverage has been considered have shown costs ranging from one cent per member per month (PMPM) (California)<sup>6</sup>; to \$0.06 (Connecticut)<sup>7</sup>; to \$.10-\$0.24 PMPM (Maryland)<sup>8</sup>.

### Potential Cost Offsets

In some cases, increased costs of added coverage may be accompanied by decreases in costs for other health care services. This is known as a “cost offset.” Implementing coverage for fertility preservation coverage would implicate two potential cost offsets:

1. New research has shown that a sizeable percentage of patients will opt for less efficacious cancer treatment due to concerns about future infertility. One study of breast cancer patients reported that fertility concerns influenced both non-initiation and discontinuation of tamoxifen treatment. The study’s authors concluded that proper information and access to fertility preservation might positively impact adherence to treatment and survivorship.<sup>9</sup> The average cost of treating early stage breast cancer over the first 24 months after diagnosis has been estimated at \$71,909; the average cost of treating stage IV breast cancer over that same

<sup>1</sup> Center for Disease Control and Prevention. United States Cancer Statistics: Data Visualizations. <https://gis.cdc.gov/Cancer/USCS/DataViz.html>. Published 2017. Accessed June 8, 2018.

<sup>2</sup> Barr RD, Ferrari A, Ries L, et al. Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future. *JAMA Pediatr.* 2016 May 1;170(5):495-501. doi: 10.1001/jamapediatrics.2015.4688

<sup>3</sup> Katsifis GE TA. Ovarian failure in systemic lupus erythematosus patients treated with pulsed intravenous cyclophosphamide. *Lupus.* 2004;13:673-678; Rovaia T, Passweg J, Heim D, Meyer-Monard S, HW. Spermatogenesis in long term survivors after allogeneic hematopoietic stem cell transplantation is associated with age, time interval since transplantation, and apparently absence of chronic GVHD. *Blood.* 2006;108(3):1100

<sup>4</sup> Quinn, G.P., Vadaparampil, S.T., Bell-Ellison, B.A., Gwede, C.K., Albrecht TL. Patient–physician communication barriers regarding fertility preservation among newly diagnosed cancer patients. *Soc Sci Med.* 2008;66(3):784-789.

<sup>5</sup> FertilityIQ. The Costs of Egg Freezing. <https://www.fertilityiq.com/egg-freezing/the-costs-of-egg-freezing>. Published 2017. Accessed July 14, 2018

<sup>6</sup> California Health Benefits Review Program (CHBRP) Analysis of Assembly Bill 912: Health Care Coverage: Fertility Preservation, A Report to the 2013–2014 California Legislature, April 25, 2013.

<sup>7</sup> UCONN Center for Public Health and Health Policy. “Review and Evaluation of Certain Health Benefit Mandates in Connecticut 2013.”

<sup>8</sup> NovaRest Annual Mandate Report: Coverage for Fertility Preservation for Iatrogenic Infertility. Prepared for the Maryland Healthcare Commission, November 16, 2017. p. 27.

<sup>9</sup> Jeruss, JS. Impact of Fertility Concerns on Tamoxifen Initiation and Persistence. *J Natl Cancer Inst.* 2015 Aug 25;107(10).

## Fertility Preservation Coverage – Key Points

time period was \$182,655.57.<sup>10</sup> The costs of treating a patient for metastatic breast cancer are significant, covered expenses. If provision of fertility preservation treatment would minimize the risk of premenopausal breast cancer patients becoming metastatic because it allows for greater levels of tamoxifen adherence it could provide a substantial cost offset to the expense of oocyte cryopreservation coverage.

2. Increased depression and anxiety along with a decreased quality of life has been well-documented in cancer patients who had unresolved infertility as a result of their cancer treatment.<sup>11,12</sup> While the costs of these sequelae have not, to our knowledge, been quantified, there are hard costs arising from both the treatment of depression and anxiety as well as secondary costs such as loss of productivity.

### Standard of Care

Patients facing iatrogenic infertility now have recognized, efficacious options for preserving their fertility prior to the initiation of their cancer treatments. Sperm, egg, embryo, and ovarian tissue banking are recognized as the current medical standard of care. These treatments are supported by all of the relevant medical associations, including the American Society of Clinical Oncology (ASCO), the American Society for Reproductive Medicine (ASRM), and the American Medical Association (AMA).<sup>13</sup>

### Rationales for Coverage

- Medical Necessity. Fertility preservation for iatrogenic infertility is not “elective” or “experimental,” but rather a needed intervention to prevent potential sterility. Patients cannot defer or forego life-saving treatments to spare their fertility.
- Address direct side effect of cancer treatment. Remedies for other side effects of treatment, such as breast reconstruction, chemo-induced anemia, wigs, prostheses, etc., typically are covered by insurance.
- Prevent additional harms and associated costs.
  - Recent studies show that significant numbers of patients make sub-optimal treatment decisions (e.g., stopping tamoxifen or choosing less gonadotoxic treatment) to minimize reproductive impact. These decisions may adversely affect both medical outcomes and treatment costs.
  - Infertility causes distress, depression, anxiety; these have financial and medical consequences, and result in overall lower quality of life for survivors.
- Access disparities. The lack of insurance coverage disproportionately affects women and those of lower socioeconomic backgrounds.
- Fundamental life activity. Loss of fertility is not merely a medical complication; it permanently affects reproduction and parenthood – fundamental life functions worthy of the highest levels of protection.

### Existing Fertility Preservation Coverage

Currently, ten states – Connecticut, Rhode Island, Maryland, Delaware, Illinois, New York, New Hampshire, California, New Jersey, and Colorado – have implemented coverage for medically-necessary fertility preservation.

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<sup>10</sup> Blumen, H. Fitch, K., Polkus V. Comparison of Treatment Costs for Breast Cancer, by Tumor Stage and Type of Service. *Am Heal Drug Benefits*. 2016;9(1).

<sup>11</sup> Letourneau JM, Ebel EE, Katz PP, et al. Pretreatment fertility counseling and fertility preservation improve quality of life in reproductive age women with cancer. *Cancer*. 2012; 118(6): 1710-1717.

<sup>12</sup> Benedict, C., Shuk, E., Ford JS. Fertility Issues in Adolescent and Young Adult Cancer Survivors. *J Adolesc Young Adult Oncol*. 2016;5(1):48-57.

<sup>13</sup> Oktay, K., Harvey, B.E., Partridge, A. et al. Fertility Preservation in Patients With Cancer: ASCO Clinical Practice Guideline Update. *J Clin Oncology*. 2018. doi:10.1200/JCO.2018.78.1914; American Society of Reproductive Medicine. Fertility preservation and reproduction in patients facing gonadotoxic therapies: a committee opinion. *Fertil Steril*. 2013;100(5):1224-1231; Association AM. Oncofertility and Fertility Preservation Treatment. <http://www.ama-assn.org/ama/pub/news/news/2013/2013-06-17-new-ama-policies-annual-meeting.page>. Published 2013.

	Medicaid Insureds	UT Cancer Incidence	Expected # cancer cases per year	# Aged 0-44	% at Risk from treatment	# age-eligible, at risk	% expected to uptake services	# patients using FP services	per unit cost
Men	182661	0.004391	802,064,451	72,185,800,59	60%	43,311,480,4	60%	25,986,89	\$ 250.00
Women	182661	0.003752	685,344,072	61,680,966,48	60%	37,008,579,9	45%	16,653,386	\$ 12,200.00

TOTAL COST	
\$	6,496.72
\$	203,177.10
\$	209,673.83