

March 6, 2023

Re: Support for Senate File 1704

Dear Senator Klein and members of the Committee:

Allow me to set the stage of what our life was like with our young son when he was diagnosed with lymphoma. We were quickly faced with making decisions about our four-year-old's ability to preserve his fertility options, at a substantial cost to us.

Imagine, if you will, your four-year-old, barely out of diapers, still a sweet, innocent toddler, waking up one day to find out he has a massive tumor in his chest that is compressing all of his vital organs, causing him to stop breathing intermittently when he lays flat and sleeps. In a flash, that innocence is ripped away, and filled in with needles, and around-the-clock medication, surgery, scans, and doctor after doctor coming to talk to you. And then you are informed that it is treatable, and the treatment is two and half years of chemotherapy. Two and a half years of toxic, cell-destroying, chemicals, every single day, which will kill cancer, but also cause a wake of physical destruction during treatment as well as for the rest of his life.

Within hours of the devastating blow you know something is seriously wrong with your baby, and your life is turned upside down, your family ripped in two while the parents' take up residence at the hospital waiting for answers and random family members are caring for your other children at home. A chest CT confirms that it is likely cancer at this point, but two days from now, your sweet innocent child will undergo surgery and have four procedures done during this surgical session, including: a port-a-cath placement (a device that is sewn into the chest wall with a line that is woven through his vein into his heart to deliver medications directly rather than have to place an IV every time), bilateral hip bone marrow biopsies, a biopsy of a lymph node from his clavicle, a lumbar puncture to check the spinal fluid to check for cancer cells, and oh, by the way, do you want a sample of his testicular tissue removed and preserved in the event that science, which is not yet developed, can someday, hopefully, be used to help him be able to have children? Mind you, we are very nervous about putting him under anesthesia, given the location and size of the tumor and the fact that when he is laid flat causes the tumor to also compress his trachea which cuts off his airway/breathing. Every minute that he is under anesthesia and laying flat is risky. Do you want to add a non-life-saving procedure to that?

In your mind, you are grappling with the fact that your baby just got his childhood ripped away from him, his innocence lost. Someone is asking you if you want to add one more cut, scar, stitch, pain, risk for your son's potential use in the future, and oh, by the way, you'll then have to pay out of pocket for the tissue to be stored every year until he decides to use it, and that's only if science has caught up and developed a way to grow that tissue to be functional for producing sperm so that he might have children. I don't want to risk his life for an extra minute, given the circumstances. The out-of-pocket cost until he is say, 30 years of age is approximately 26 years of out-of-pocket payments for something he may not want, or may not even be usable courtesy of medicine. Will he be angry if we don't? Will he be in more pain if we do? How will we explain this extra pain and stitches to him? How will we someday have this discussion when he's an adult? What if something happens to him while he's in surgery, and I forever question whether the additional procedure that I opted for was just enough to push him over that threshold of tolerance? I would never forgive myself.

We don't have time to think. It's now or never. Chemo may likely abolish his chances of being able to have children long before he can comprehend any of this. And the decision, in the midst of everything else we've just been hit with, is ours to make, right now. No going back.

He is four. Four.

Stop.

Think about that.

Try to wrap your head around that.

Just after being told our son had cancer, the doctor mentioned a research study with no guarantees, but that getting a procedure prior to treatment COULD POSSIBLY help in the future. In speaking with other families not initially diagnosed at a premier academic medical center this step is often missed.

Thinking back, it's so surreal all the decisions a parent must make on the spot after getting blindsided with a childhood cancer diagnosis. Cancer should be the only thing you have to cope with.

We currently pay \$250/year out of pocket to keep tissue preserved. So, essentially have paid \$1,000 since diagnosis and will need to keep tissue frozen until at least puberty if not longer out of pocket. If we do not pay, the tissue is discarded – all this on top of the cost of the initial procedure.

We ask your support of Senate File 1704.

Sincerely,

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