Fertility Preservation in Pediatric Cancer Patients
How to Advocate for State-Level Insurance Benefits

Alex Huron, MD, Brian Duty, MD, MBA, Casey Seideman, MD

Oregon Health & Science University

The Clinical Need

- Long-term survival rates of 80% are common for pediatric cancers and about 25% of patients are > 30 years from diagnosis[2]
- Treatment regimens for these common cancers include chemotherapy, radiation, and surgery, all of which pose significant fertility risk[2]

Diagnosis



Average Time: 2-3 wks

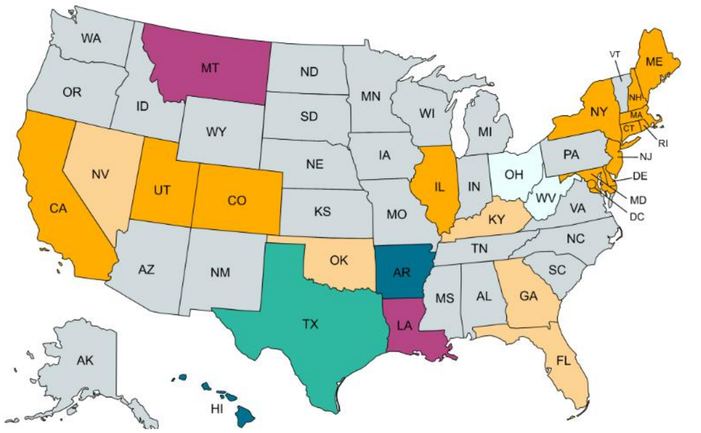
Treatment



Barriers to fertility preservation

- Financial Toxicity
- Caregiver Stress
- Patient & Family Education

A 2019 study reported live birth rates between 27%-28% percent after transplantation of preserved ovarian tissue



Designing our Approach

The Utah Case Study:

- Identify a clinical need: “pediatric fertility preservation”
- Involve legislators with personal experience with the matter at hand
- Build consensus within a broad network of physicians, patients, and key stakeholders
- Apply winning framework to achieve broader-scale legislative efforts

Key Partnerships	Engage w/ State legislators with medical backgrounds who appreciate the scope of the problem **Senator Lisa Reynolds**	Recruit Industry groups with subject matter and lobbying expertise **Oregon Pediatric Society, ACS**
Institutional Support	Work with institutional key stakeholders to generate a unified message **OHSU Governmental Affairs**	Highlight how our initiative may align with a broader institutional legislative agenda **OHSU, DCH**
Financial Impact	Highlight and consistently emphasize the near neutral cost of our initiative	Juxtapose the lower cost of our specific, focused initiative with a broader, less attainable, but highly popular ask

SUCCESS: BILL DRAFTING
DRAFT LEGISLATION CURRENTLY BEING CONSIDERED AT THE HOUSE LEVEL

Next Steps

Conduct a Cost analysis	Build a Legislative coalition	Support groups & affected patients
• Leverage advocacy network, industry partners, and legislative offices to quantify full impact	• Promote initiative to legislators on both sides of the aisle within both chambers of house	• Provide legislators with tangible, meaningful patient examples to highlight impact

→ Final Legislation and Policy Change

Challenges: Institutional buy in, challenging financial headwinds

Lessons Learned: Consensus is key, industry partnerships matter, legislators with experience are golden