

# Advocacy for fertility care

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At the New England Walk of Hope a few years ago, I met a family whose young daughter was showing off her T-shirt emblazoned with the words, “I am a work of ART.” This little girl was beaming with pride because she had decorated the shirt herself with thick, colorful puffy paint. Her parents were smiling because the “ART” being referenced was Assisted Reproductive Technology (ART).

This child, conceived through fertility treatment, is special though not unique. More than 8 million babies worldwide have been born via ART, such as in vitro fertilization (IVF).<sup>1</sup> However, widespread insurance coverage for fertility treatment remains elusive in the United States, with most states in the nation still lacking fertility insurance laws. Thankfully, there are signs of progress that are cause for hope and celebration. Advocacy from the fertility community, comprised of those who personally know the struggle of building a family and health care providers, is more important than ever. But how do we advocate for improved access to fertility treatment? As is often the case, we benefit from both looking back and looking ahead.

## What we mean by advocacy

Merriam-Webster defines advocacy as “the act or process of supporting a cause or proposal.”<sup>2</sup> One can advocate at various levels: individual, group or political. The cause can seem large or small. You can advocate for yourself, for others or for a greater good that might be a combination of the two. No matter what, to me, the key word in the definition is “act.” To advocate, you need to take action of some kind. You cannot be silent.

While all types of advocacy are profoundly important, this article will focus on advocating for policy change through the government. My mentor and friend, Judy Meredith, describes this kind of advocacy as getting “the right information to the right person at the right time.”<sup>3</sup> I believe I heard this definition more than 20 years ago, but it is still my favorite. As Meredith explains further in *Lobbying on a Shoestring*, “Get accurate, compelling, sympathetic, and completely factual information ... to the appropriate policy maker before he or she decides about your policy initiative.”<sup>3</sup>

## Reaching those who represent you

Meredith’s description speaks to many important aspects of advocacy. Perhaps foremost is the idea that the most important policy makers are *your* policy makers—whoever represents you at the local, state and federal levels based on your home address. These elected officials work for *you*. U.S. Rep. (and now U.S. Sen.) Tammy Duckworth

delivered an emphatic reminder of this when she spoke at the 2016 Advocacy Day, sponsored by RESOLVE: The National Infertility Association. The advocates in attendance were about to head off to their meetings on Capitol Hill. Duckworth, who became a mother through IVF, passionately said, “Congress isn’t my house, it’s your house.”<sup>4</sup> I got chills!

Over the years, many people have sheepishly admitted to me that they do not know the names of their legislators. There is no need for shyness or embarrassment. However, this is the first step of advocacy: Find out who your elected officials are and how to contact them. You can begin by searching online for something like, “Who represents me?”

Once you know who represents your district, you can participate in grassroots advocacy, which is when concerned members of the general public are encouraged to “contact their local, state or federal officials regarding a certain issue.”<sup>5</sup> This outreach can take various forms, including emails, phone calls, letters or meetings. Whatever the form, the key is to act when your voice is needed while personalizing your message some way (not a form letter!). You bring expertise and passion to the policymaking process. It can be very compelling and persuasive for elected officials to hear directly from people who are personally affected by an issue.

## Access to fertility care

Several political issues impact patients and providers involved in fertility care. In this article, I focus on one of the central policy matters for our field—insurance coverage for fertility treatment. There is currently no federal law related to insurance coverage for fertility care. However, 19 states have enacted their own fertility insurance laws.<sup>6,7</sup> Many refer accurately to such laws as “mandates” because they institute requirements of private market health insurance, though the specific types of coverage in these laws vary widely from state to state.

In the United States, most fertility insurance laws can be described as either a mandate to cover or a mandate to offer. The distinction between the two is important. According to RESOLVE, a mandate to cover is “a law requiring that health insurance companies provide coverage of infertility treatment as a benefit included in every policy (policy premium includes cost of infertility treatment coverage).”<sup>8</sup> On the other hand, a mandate to offer is “a law requiring that health insurance companies make available for purchase a policy which offers coverage of infertility treatment (but the law does not require employers to pay for the infertility treatment coverage).”<sup>8</sup>

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In this article, I use my preferred term, “fertility insurance law” because the word “mandate” can raise the expectation that these laws require universal coverage. Unfortunately, none of them do. There are always exemptions, even in states with robust laws. This includes the fact that self-insured (sometimes called self-funded) plans follow federal law and do not need to adhere to state laws, though some employers voluntarily choose to do so.<sup>6</sup> Regardless of the differences within and between states, it is crucial for more states to pass fertility coverage bills, as these laws significantly improve access to care for those who need treatment to try to conceive.

I am pleased to highlight a few campaigns that have led to fertility insurance laws in the United States. These and other recent legislative victories give great hope to our community that more states will recognize the importance of expanding fertility coverage. This is by no means an exhaustive list, but these examples provide some helpful advocacy lessons.

## Massachusetts

Maryland was the first state in the nation to enact a fertility insurance law in 1985. However, it was a Massachusetts bill that was the most comprehensive at the time. Experiences related to passing that legislation highlight some critical aspects of effective fertility advocacy.

First, the campaign in the Commonwealth benefited from having both patients and providers share their perspectives during the legislative process. RESOLVE, with leadership from patients Martha Griffin (also a nurse), Susan Crockin, Karen Sweet and Bob Sweet, led the advocacy effort in Massachusetts. Their first step was to persuade state Sen. Edward Burke to be the lead sponsor of the bill, which was introduced in 1986.<sup>9</sup> Clinicians played an important role, joining patients in testifying when the legislation had its committee hearing.

Another important part of the success in Massachusetts was the effective use of grassroots advocacy. The fertility community wrote letters and made phone calls to their own lawmakers in support of the fertility bill. One lobbyist remembers the Massachusetts campaign this way, “I think [RESOLVE] got every single person in their membership at some point in time or another to write a letter. ... [The legislators] were inundated with this stuff. ... It was personal stories, one after another after another. You can’t deny people’s pain. You can deny a lot of things, but not personal pain.”<sup>10</sup>

Though it might seem like simply writing or calling your elected officials does not matter, experiences like this demonstrate otherwise. Advocacy humanizes the issue and helps one subject get attention amidst a huge volume of other policy matters. Only private insurance companies and the Roman Catholic Church opposed the Massachusetts bill at the hearings. Burke, a Catholic, wrote a letter to Cardinal Bernard Law of the Archdiocese of Boston that read, “If you have not yet had the opportunity

to meet with a married couple holding their newborn child as a result of invitro [sic] fertilization, I suggest that it would be most difficult for you in good conscience to tell them they have done something immoral.”<sup>11</sup>

The bill passed the Massachusetts legislature in 1987. It went to the desk of Gov. Michael Dukakis, who heard from many grassroots advocates and subsequently signed the bill into law. I have personally heard him describe the passage of the Massachusetts fertility insurance law as one of the most gratifying parts of his time in the corner office of the Commonwealth.

## Delaware

Several states passed fertility insurance laws in the decade following enactment in Massachusetts, including Rhode Island, Connecticut, Illinois and New Jersey. Then, nearly two decades passed before fertility insurance law was enacted in another state. In Delaware, patient advocate Christie Gross spearheaded efforts that resulted in the passing of a fertility insurance bill in June 2018. This success was particularly notable, not only because it occurred well after legislation in other states, but also because it was the first fertility insurance law in the nation to include coverage requirements for both infertility care and medically necessary fertility preservation. The victory was the result of the tireless efforts of Gross and her fellow advocates, comprised again of both patients and providers.<sup>12</sup>

## New Hampshire

Inspired by the success in Delaware and motivated by the widespread lack of fertility coverage in New Hampshire, Resolve New England (RNE) launched an advocacy campaign in the Granite State during the summer of 2018. I joined with Davina Fankhauser, co-founder of Fertility Within Reach (FWR), as well as attorneys/RNE board members Chrissy Hanisco and Catherine Tucker, to draft a fertility insurance bill for New Hampshire.

Fertility coverage bills had been introduced in New Hampshire over the previous 20 years without success, but this piece of legislation was new. Many state, regional and national organizations joined RNE and FWR in supporting SB 279 throughout the legislative process. The most powerful advocacy came from many Granite Staters who shared their personal experiences with fertility challenges.

Fertility nurses also helped bolster the campaign. In addition to contacting their own state legislators, nurses provided in-person and written testimony for the committee hearings. Nicole Ouellette, a nurse from Boston IVF, was among those who testified before the New Hampshire House of Representatives Committee on Commerce and Consumer Affairs. Ouellette powerfully discussed her clinical perspective on the challenges for fertility patients who cannot afford treatment, as well as her personal struggles to grow her family.

In the New Hampshire campaign, getting the right information to the right elected officials at the right time meant focusing extra attention on key members of the committees where the bill would be heard. We also proactively pursued bipartisan support, particularly among the bill's co-sponsors. The culmination of this was that all New Hampshire senators, regardless of party, voted in favor of the legislation. The bipartisanship also helped dispel the myth that fertility coverage is only a Democratic issue. As our community knows all too well, fertility challenges affect people of all political parties, races, sexual orientation and economic levels.

SB 279, requiring group insurance coverage for both fertility treatment and fertility preservation, passed the legislature in June 2019. Gov. Chris Sununu signed it into law on Aug. 1, 2019, and it took effect on Jan. 1, 2020.<sup>13</sup>

## Colorado

During the 2020 legislative session in Colorado, advocates filed a comprehensive bill titled, "Insurance Coverage for Infertility." Colorado Fertility Advocates (CFA), in partnership with a broad coalition of patients, providers, state partners and national organizations, including RESOLVE and the Alliance for Fertility Preservation, led the campaign.<sup>14</sup> CFA board member, Crystal Wilson, shared her thoughts with me on the significant role of nurses in the campaign efforts: "Nurses are an invaluable part of any fertility journey. As patient advocates, they help guide you through unimaginable times. As legislative advocates, nurses bring vital skills and incredible hearts to break down the barriers to accessing fertility care."

The bill passed the legislature, and Gov. Jared Polis signed it into law on April 1, 2020, in the midst of the COVID-19 pandemic. In his bill-signing statement, Gov. Polis stated: "Infertility is clearly and demonstrably a source of significant expense, as well as depression and great sadness for many Coloradans. Couples are infertile for a host of reasons, including because of cancer or wounds sustained in combat. The bill will help families have children in the wake of COVID-19 and is important for our state's future economic success."<sup>15</sup>

## You are not alone

One of the mantras of the family building community is to reassure people that they are not alone, even when it feels like they are the only ones struggling to grow their families. Similarly, no one needs to pursue advocacy alone. Finding like-minded partners and groups can make it quick, easy and even fun to communicate with your elected officials. Resources specific to the fertility community include RESOLVE, FWR, and RNE. Organizations like these can provide information about relevant advocacy efforts at the federal or state levels.

One great option for those who want to get more involved is Advocacy Day, which is co-sponsored by RESOLVE and the American Society for Reproductive Medicine. Typically held in Washington, D.C. each spring, this event was held virtually for the first time in 2020 with advocates representing all 50 states. At Advocacy Day, no one is flying solo. Participants receive training and join with other advocates throughout the day to meet with legislative offices.<sup>16</sup> This is a great forum for patients or providers who want to learn how to advocate and put these lessons immediately into practice. As newcomers will discover, the more you advocate, the more comfortable you become. Each of us can make a significant impact on improving access to fertility care. Sharing your voice, expertise and dedication really does make a difference.

## About the author

Kate Weldon LeBlanc is the executive director of Resolve New England (RNE), an independent nonprofit organization dedicated to building a caring community in New England to support, inform and advocate for all those struggling with fertility and family building. Having experienced years of infertility, LeBlanc and her husband Joe are the extremely grateful parents of 12-year-old Sophie. In 2007, newly pregnant after IVF, LeBlanc attended a celebration of the 20th anniversary of the fertility insurance law in Massachusetts. In 2017, she organized the 30th anniversary celebration as RNE Director, and Sophie joined her at the event.

LeBlanc is proud to be one of the co-authors of the New Hampshire fertility insurance bill that became law in 2019. She is an active member of the New England Fertility Society, for which she currently serves as secretary. Prior to her arrival at RNE, she worked for the Center for Early Relationship Support of Jewish Family & Children's Service, the Child Advocacy and Government Relations departments of Boston Children's Hospital, and the Massachusetts Legislature.

A commitment to advocacy has been the common thread throughout her career. LeBlanc holds a Bachelor of Social Work from Skidmore College and a Master of Public Administration from University of Massachusetts Boston.

## References

1. Adamson GD, de Mouzon J, Chambers G, Zegers-Hochschild F, Mansour R, Ishihara O, Banker M, Dyer S. International Committee for Monitoring Assisted Reproductive Technology: world report on assisted reproductive technology, 2011. *Fertil Steril* 2018. Nov;110(6):1067-1080. doi: 10.1016/j.fertnstert.2018.06.039.
2. "Advocacy." Merriam-Webster.com Dictionary, Merriam-Webster, <https://www.merriam-webster.com/dictionary/advocacy>. Accessed July 20, 2020.
3. Meredith JC, Monsell ME. *Lobbying on a Shoestring*. 4th ed. MCLE, Inc.; 2018:8. Accessed June 25, 2020. [http://www.realclout.org/?page\\_id=1862](http://www.realclout.org/?page_id=1862)
4. Jones G. 5 lessons from Advocacy Day that will teach you to never mess with the infertility community. Fertility Bridge website. Published May 17, 2016. Accessed June 25, 2020. <https://www.fertilitybridge.com/inside-reproductive-health/2016/5/16/nevermesswiththeinfertilitycommunity-advocacyday>
5. Grassroots advocacy 101: a brief guide for anyone newly involved in political advocacy. Muster website. Published June 7, 2016. Accessed June 25, 2020. <https://www.muster.com/blog/grassroots-advocacy-101-a-brief-guide-for-anyone-newly-involved-in-government-relations>
6. State infertility insurance laws. American Society for Reproductive Medicine website. Accessed June 26, 2020. <https://www.reproductivefacts.org/resources/state-infertility-insurance-laws/>
7. State policy updates. ASRM Bulletin. American Society for Reproductive Medicine website. Published April 2, 2020. Accessed July 20, 2020. <https://www.asrm.org/news-and-publications/news-and-research/press-releases-and-bulletins/state-policy-updates/>
8. Health insurance 101. RESOLVE: The National Infertility Association website. Accessed June 26, 2020. <https://resolve.org/what-are-my-options/insurance-coverage/health-insurance-101/>
9. Britt EC. *Conceiving Normalcy: Rhetoric, Law and the Double Binds of Infertility*. The University of Alabama Press; 2001:60.
10. Britt EC. *Conceiving Normalcy: Rhetoric, Law and the Double Binds of Infertility*. The University of Alabama Press; 2001:62.
11. Britt EC. *Conceiving Normalcy: Rhetoric, Law and the Double Binds of Infertility*. The University of Alabama Press; 2001:65-66.
12. Wolf P. Delaware strives to be first in fertility care. Delaware Today website. Published April 17, 2019. Accessed June 26, 2020. <https://delawaretoday.com/life-style/family-kids/delaware-strives-to-be-first-in-fertility-care/>
13. New Hampshire expands fertility coverage to employer-sponsored health plans [news release]. American Society for Reproductive Medicine; August 2, 2019. Accessed June 26, 2020. <https://www.asrm.org/news-and-publications/news-and-research/press-releases-and-bulletins/new-hampshire-expands-fertility-coverage-to-employer-sponsored-health-plans/>
14. Colorado Fertility Advocates website. Accessed June 26, 2020. <https://coloradofertilityadvocates.org/>
15. Gov. Polis signs bills into law. Colorado Governor Jared Polis website. Published April 1, 2020. Accessed June 26, 2020. <https://www.colorado.gov/governor/news/gov-polis-signs-bills-law-19>
16. Advocacy Day. RESOLVE: The National Infertility Association website. Accessed June 26, 2020. <https://resolve.org/get-involved/events/advocacy-day/>

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