

My name is Amy Arcand. On October 31st 2017 I gave birth to a beautiful 6 pound 4 ounce baby girl. Her name was Bailey and she was our missing piece. On July 5th 2018, four short days after my girl turned 8 months old, my husband Kody, and I woke up to find that our sweet little girl had passed away in her sleep. She is forever our perfect sleeping angel. After months of not knowing what happened and still trying to understand that it had even happened, we finally got a phone call from the coroner saying that our Bailey had died due to her having tumors in her heart. This caught us off guard, she never had a side effect, her checkups were regular, her shots were up to date, no one ever mentioned that they noticed anything to be wrong. Later we found out it was a side effect of a genetic defect called Tuberous Sclerosis Complex (TSC) that was passed down from my husband.

After discussions with our doctor and personal research we discovered TSC is a dominant gene. Meaning if we were to try having another baby using the traditional method, we would run a 50-50 chance of ending up with another devastating heartache. A 50-50 chance that we could have another baby or that we could have another baby die...

I don't expect you to understand where we are coming from, but try to imagine for a moment. Imagine your life being the life that you had always hoped, dreamed, and worked for. The perfect idea of your life, everything being just the way you've ever wanted. Now imagine it all crashing and going away in a single millisecond. Everything you have ever hoped for, just gone, and there's nothing you can do to change the outcome no matter how hard you beg and plead. This is your life now. Not understanding, yearning to feel whole again, wanting what you worked so hard for to come back, wishing your arms were not empty. Now, imagine someone telling you "oh, it's okay you can just have another one" like that bandaid is going to fix the whole in your chest where your heart used to be. This is your life now. You just wanting your life back and everyone minimalizing the tragedy you just went through and the magnitude of it and the magnitude that you now face trying to get your life back to a "normal"

We have met with infertility doctors and discussed our options, discussed expenses and insurance coverages. All to find out that no matter what we choose we are looking at a minimum of \$20,000-\$25,000 just to have the chance to have a healthy baby. All due to the fact that we have not been infertile for 2 years, our insurance will not consider us as eligible. Now imagine having that weight on your shoulders.

Paying \$20,000 out of pocket to try to have another baby, with no guarantee that it will work. \$20,000 for one, ONE, round of IVF. \$20,000+ in debt just to have the chance of having a healthy baby.

It has been made so easy for women in the United States to decide that they don't want their babies and can choose to abort them. Why is it so easy to take a life and so hard to give one? If you would, please consider passing HB1147. In doing so you could give those of us who want babies that same chance that has been given to those who don't want them. Passing HB 1147 will help give hope to those of us that want the chance to have our own family with out having to go years into debt

Thank you,
Amy Arcand
Williston ND
(701) 651 7377
loganamy1973@gmail.com

Dear North Dakota State Lawmakers:

I think there is a misconception that when we are asking for infertility coverage in North Dakota, we are only asking for IVF coverage. Many people do not need IVF for building their families, and others don't want to go that route for various reasons. Some just need a few medications, ultrasounds, or quick procedures, but even those costs quickly pile up when your chart says "infertility." Insurance won't cover a thing once you have been labeled "infertile" in your medical record. Some diagnostic tests are avoided due to cost. Providers want to give you your best chance and their best care, but they are bending over backwards trying to keep the expense low and your chances high. Sometimes providers are unable to see the whole picture because of the cost avoidance.

My husband and I have been trying to grow our family for four and a half years. We gave medical interventions a try for just about a year toward the beginning of our marriage, and quickly racked up over \$12,000 in medical bills. This cost includes 4 medicated cycles using the drug Femara to help me ovulate on my own. We followed that with 3 more cycles of Femara, ultrasounds to check follicle growth, a shot called Ovidrel to trigger ovulation once my follicles were the right size to release an egg, and intrauterine insemination (IUI). IUI is the medical term for placing sperm directly in the uterus. You've maybe heard of this referred to as the "turkey baster method." After our efforts became too expensive and emotional for us to continue, we decided to stop treatments and go a less expensive, but still out of pocket direction.

We have had two pregnancies in the past two years after trying natural supplements, homeopathic testing, massage, etc. Unfortunately we lost both pregnancies for unknown reasons other than low progesterone. Low progesterone could be part of the reason we are not falling pregnant in the first place. Our miscarriages could give us insight into our infertility issues, but again, because of the lack of insurance coverage for diagnostic testing for infertile women and men, we don't have many of the answers that could very well guide us toward a successful pregnancy.

My biggest dream for the last 4 years has been to carry and give birth to a healthy child. I am finding bigger purpose in our struggles, and that is through infertility advocacy and awareness. Even though this is deeply personal to share, I know writing this is may make the difference in a yes or no vote to help North Dakotans gain better access to care for growing their families. Please vote "yes" to HB 1147.

All the best,

Mikayla Atchison

Committee members,

I knew I would have trouble getting pregnant, so when my husband and I decided to try and get pregnant I knew it was going to be an uphill battle. After a year of just trying and nothing, I decided it was time to get help because it's pretty hard to get pregnant without a menstrual cycle. We knew we could never afford IUI or IVF so decided to try some medicated rounds but only a few, since those weren't covered either. With 2/3 trips a week for a month and a half to a town 90 minutes away one way, we started the process. Not only were the medications not being covered, I had to add on gas and miles upon miles to my vehicle. Once the bills started rolling in for all the medications, ultrasounds, doctor visits etc., my husband and I decided we could only afford one more round if this one didn't work. Infertility is already a very emotional hardship and adding on a financial burden doesn't help.

Wendy Eszlinger

Ashley ND District 28

Support House Bill 1147

Dear Committee Members,

I am writing to ask for your support of a bill that will help many North Dakotans who are struggling with infertility.

One in six couples will struggle with infertility. I happen to be one of those six.

After trying for a year to build a family ourselves, we reached out for help. After several tests we found out I had Poly Cystic Ovarian Syndrome. This is where our journey began. We started having monthly lab draws and bi weekly ultrasounds. Multiple doctor appointments every month. I took oral medication to help produce healthy eggs. After this process failed twice, we were referred to an endocrinologist. He suggested we keep doing this process and also incorporate Intrauterine Insemination (IUI). After 5 failed IUI's and 2 years later, we were told our last resort was In Vitro Fertilization (IVF). What people do not see in this two year struggle is how hard this journey is mentally, physically, emotionally, and financially. I became depressed toward the end of this process. Having to look my husband in the eyes month after month and tell him it didn't work again became harder and harder. I started to withdraw socially. Going out with friends and listening to them talk about their children was exhausting. I wanted so badly to be a mother.

Financially the bills kept pouring in. The minute the diagnosis of infertility was attached to me, my insurance quit covering costs. When we found out IVF was our only option we had to sell vehicles in order to make our down payment of \$11,500. That initial cost doesn't include the \$1,500 worth of medication I needed for two weeks along with all the lab work and Ultrasound scans I had weekly prior to IVF. Did you know that an initial hormonal panel can cost \$800? That is what I paid out of pocket for one lab draw. This process is financially draining because insurance does not cover it or they give you a once in a life time amount to spend. That amount does not go very far when each cycle you go through costs hundreds and sometimes thousands of dollars depending on the procedures you need to have done. The fact that insurance can deny families even the chance of trying to conceive a child of their own is downright wrong. The financial burden of these medical costs for fertility treatments are what deny a lot of families the chance to even try to conceive their own child.

House Bill 1147 requires health insurance providers to provide coverage for the diagnosis and treatment of infertility. The bill complies with current medical standards of care for those affected by infertility, including coverage for fertility preservation treatments to allow women and men to preserve their fertility before undergoing cancer treatment or other medical procedures.

I hope you will support this pro-family bill. My hope is that in the future my daughter, whom was conceived through IVF, will have support financially and insurance coverage should she ever need it, to start a family of her own.

Sincerely,

Brooke Borlaug

District 33

Dear Committee Members,

My husband and I were married in 2010. We wanted to start a family immediately. However, it quickly became apparent that we had significant fertility issues. At the time, I was employed and the health insurance provided by my job covered up to \$20,000 of medical services. This seems like a lot, but is quickly used up with testing, procedures, medications, ultrasounds, IUIs. When we reached the decision to do IVF, it took multiple rounds and most was paid for out of pocket. Along with cost of travel out of state. A few years later when we wanted to expand our family, the insurance provided by my husband's job did not cover anything. We paid for 4 rounds of IVF. Flights out of state. Hotels. All out of pocket. We used our savings and had to borrow money from our in-laws.

On top of the financial burden, the stress on our mental health was great. Once again, our health insurance did not provide great coverage for mental health services. Please pass HB 1147.

Chelsey Moore
District 1

Dear Chairman Lefor, Vice-Chairman Dever, and distinguished members of the Employee Benefits Programs Committee,

I am writing in support of House Bill 1147: An Act to create and enact section 54-52.1-04.19 of the North Dakota Century Code, relating to public employee fertility health benefits

The bill is designed to provide comprehensive, yet reasonable, insurance coverage for infertility diagnosis, fertility treatment, and fertility preservation. The bill was co-authored by myself, Davina Fankhauser of Fertility Within Reach, and William Harrie of Nilles Law in Fargo, ND. Along with patient advocate, Tara Brandner of Everlasting Hope, we shared the language of the bill with local insurance carriers, medical professionals, and attorneys to ensure the requested coverage before you would work for North Dakota.

According to the National Institutes of Health, approximately 9% of men and 11% of women of reproductive age in the United States have experienced fertility problems. "Infertility" is a term used to describe the inability of a couple to get pregnant or the inability of a woman to carry a pregnancy to term. 3% of these individuals will require Assisted Reproductive Technology (ART), such as in vitro fertilization (IVF), to treat the disease of infertility. We want them to have access to quality fertility care and coverage in North Dakota. In doing so, we provide timely and appropriate health care, optimizing safe pregnancies and healthy babies.

Many national and global health organizations, including the American Medical Association, designate infertility as a disease, yet in North Dakota it is not covered by insurance like other diseases.

While there are some self-insured employers offering fertility benefits, we want more residents of this great state to have this as well. This bill is comprehensive to cover fertility treatment in such a way to increase chances of live births, reducing utilization of benefits associated with mental health, high-risk pregnancy, and NICU expenses.

Through my professional background, advocating for fertility health benefits over the past 16 years, HB1147 was created learning from the mistakes of previous states and copied what has worked best in other states with mandated benefits. For instance, we've learned to use language which protects men experiencing male factor infertility, recognizing their disease, and providing benefits without having to undergo non-medically necessary treatments first. In addition, we know in some states, insurance carriers are voluntarily offering insurance benefits for fertility preservation. This indicates that providing benefits is a reasonable and affordable ask and we see proof in that over the past four years, ten states have adopted laws providing benefits for fertility preservation.

States and insurers recognize, one of the most effective strategies in the realm of preventative medicine is to bank reproductive cells when medically necessary. The cost of preserving fertility ranges based on the treatment protocol, age and gender of the patient. The procedure for men,

while significantly less than women, is also a financial burden. My nonprofit recognized an underserved population and began a grant program called Banking on the Future. We pay for the first year of storing cryopreserved material for those 21 years and younger and negotiated discounted rates of storage for subsequent years. Parents of children in need are overwhelmed by the additional expense and often, regretfully, choose not to preserve their child's fertility. It does not need to be this way. North Dakota can help both youth and adults have health and hope for their future.

For established laws that provide for the diagnosis of infertility, fertility treatment (in some states unlimited benefits), and fertility preservation, the national average per member per month (PMPM) cost to an individual's premium is \$1.39. Most states find these benefits are 1% or less of the total health care costs. These laws have been in place for decades and have become part of the fabric of the states' health care system.

The lack of widespread fertility coverage in North Dakota not only negatively impacts the health of the patients, but it also negatively impacts the state's economy. We want North Dakota to be competitive as it relates to attracting and retaining a young workforce. Should you favorably report HB 1147 out of committee, you will help 1 in 6 couples be able to buy a car, a house, contribute to the economy in general as well as their retirement. As is, the 1 in 6 save every penny, sell their homes, to afford healthcare to treat their disease.

We want North Dakota residents to have the best fertility care, guided by medical need and state-of-the-art medical expertise, not financial limitations. It is our hope that you will Favorably vote HB1147 out of committee so it may move forward in the legislative process.

For additional information, I have attached The Policymaker's Guide to Fertility Health Benefits. This will share details related to costs, quotes from insurance executives, as well as citations which support all evidence-based data provided.

Thank you for your time and consideration. I am available to address any questions you may have.

Sincerely yours,



Davina Fankhauser

Co-Founder and President

Fertility Within Reach, Inc.

P: 857.636.8674

E: admin@fertilitywithinreach.org

A: 1005 Boylston St #332, Newton Highlands, MA 02461-1318

www.fertilitywithinreach.org

The Policymaker's Guide to Fertility Health Benefits

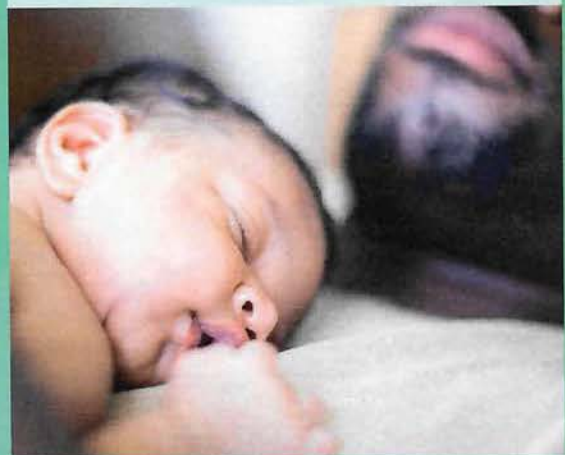
Evidence-Based Data for Informed Decisions



Fertility Within Reach.
ADVOCATING FOR FERTILITY HEALTH BENEFITS

“ I can honestly say with 100% certainty that our son Jake would have *never* been conceived if my employer had not offered us a health insurance plan that included IVF coverage.”

Rob Walden
Resident of Mesa, Arizona



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Infertility: The Facts¹

A Silent Problem that You Can Help Address

HOW MANY PEOPLE ARE AFFECTED BY INFERTILITY?

1 in 6 couples in the U.S. are affected by infertility.²

WHAT IS INFERTILITY?

Infertility is a disease of the reproductive system, resulting in not being able to conceive after one year of trying (or six months if a woman is older than 35). Women who can get pregnant but are unable to stay pregnant are also infertile.

WHAT CAUSES INFERTILITY?

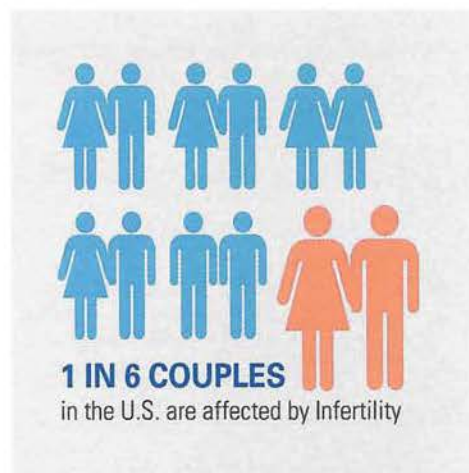
Approximately one-third of infertility is due to male factors such as azoospermia (no sperm cells), congenital disorders (disease or physical abnormality present from birth), and trauma. Another one-third of infertility is related to female factors including, but not limited to, endometriosis, ectopic pregnancy, uterine fibroids. The remaining one-third of infertility can be attributed to problems in both partners or is unexplained.

WHO IS AFFECTED BY INFERTILITY?

Both men and women experience infertility equally.

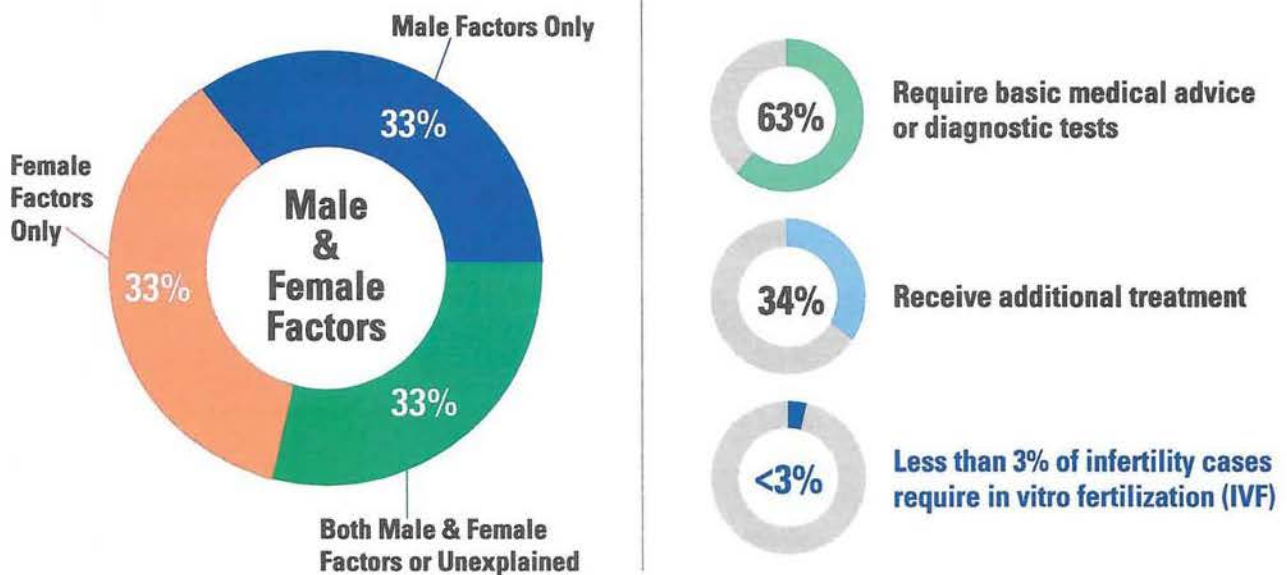
HOW IS INFERTILITY TREATED?

3% of infertility cases require assisted reproductive technology (ART), such as in vitro fertilization (IVF). In some ART cases, patients require third party reproduction (donor egg, donor sperm, donor embryo, or gestational carriers) due to medical conditions or treatments resulting in poor egg or sperm quality, or conditions that make carrying a pregnancy unsafe. 97% of infertility cases are treated with conventional drug therapy or surgical procedures.



In 1998, the U.S. Supreme Court stated that reproduction is a "major life activity," and "**conditions that interfere with reproduction should be regarded as disabilities,**" as per The Americans with Disabilities Act of 1991.⁴

CAUSES OF INFERTILITY⁵ & REQUIRED TREATMENTS



WHAT LEGAL PROTECTIONS DO INFERTILITY PATIENTS HAVE?

U.S. and district courts have ruled individuals with infertility can have accommodations and protections under The Americans with Disabilities Act and The Family Medical Leave Act.

United States Supreme Court

Bragdon v. Abbott, 1998

In 1998, the Supreme Court of the United States ruled, in *Bragdon v. Abbott*, that infertility was considered a "major life activity" and could be included within The Americans with Disabilities Act.

District Courts

LaPorta v. Wal-Mart, 2001

District court case *LaPorta v. Wal-Mart* found infertility could constitute a disability under The Americans with Disabilities Act. Approval of an employee's requested day off for infertility service, even with short notice, would be considered a reasonable accommodation.

Culpeper v. BlueCross BlueShield of Tennessee, 2013

In *Culpeper v. BlueCross BlueShield of Tennessee*, the district court found an employee could demonstrate that his or her infertility, or that of his or her spouse, constitutes a serious health condition under The Family Medical Leave Act and thus has protection.

Fertility Preservation

WHAT IS FERTILITY PRESERVATION?

Fertility preservation involves medical procedures to protect cells such as sperm, eggs, or reproductive tissue so that a person can use them in the future to have biological children. The process of cryo-preserving reproductive cells is considered standard medical care conducted by experts in assisted reproductive technology. People with certain diseases, disorders, and life events that affect fertility may benefit from fertility preservation.⁶

STATES RECOGNIZE THE IMPORTANCE OF FERTILITY PRESERVATION

MASSACHUSETTS (2012)

Insurers voluntarily offer fertility preservation benefits.

CONNECTICUT (2017)

Governor signs into law *Melissa's Law for Fertility Preservation*

RHODE ISLAND (2017)

State expands infertility benefits to include fertility preservation.

MARYLAND (2018)

Law makers add fertility preservation to state's existing healthcare coverage.

DELAWARE (2018)

State gains an infertility law, which includes fertility preservation.

ILLINOIS (2018)

Law makers amend existing healthcare law to include fertility preservation.

NEW YORK (2019)

State expands infertility benefits and includes fertility preservation.

NEW HAMPSHIRE (2019)

State gains fertility care law, which includes fertility preservation.

CALIFORNIA (2019)

Governor signs into law fertility preservation benefits for cancer patients.

NEW JERSEY (2020)

State expands infertility benefits to include fertility preservation.

PREMIUM IMPACTS

The Maryland Health Care Commission estimated the potential impact on insurance premiums for coverage for fertility preservation would result in 0.4% to 0.6% increase per month (PMPM).⁷

California Health Benefits Review Program discovered the insurance premium increase to provide fertility preservation benefits for small-group and individual markets came to only \$0.0092 PMPM.⁸

Common Fertility Misconceptions & Truths

MISCONCEPTION

Fertility treatments are excessive. People can have a family if they just relax or adopt a child.

TRUTH

Timely and appropriate healthcare is offered to optimize the use of recommended treatment and increase the number of safe pregnancies and healthy babies.

There is no scientific evidence to support “relaxation” as a reliable treatment to overcome the disease of infertility.

Adoption is not a reliable option for all. Private adoption can be expensive, and unaffordable to most couples. Adopting a foster child is an unreliable option since the goal of foster care is to reunite children with their biological family.

MISCONCEPTION

Insurers are opposed to covering fertility treatments such as IVF, due to cost.

TRUTH

“All clinics in Aetna’s Institutes of Excellence network for infertility services offer elective single embryo transfer (eSET). Research shows that transferring one embryo at a time results in dramatically lower rates of twins and multiple births, and can thereby reduce the associated health risks.”⁹

James D. Cross, M.D., Former Vice President of National Medical Policy and Operations, Aetna

“Multiples are more likely to require long stays in the neonatal intensive care unit (NICU), which increases costs. It’s important for employers and health plans to connect the dots between the cost of the infertility benefit and the significant savings on the maternity and neonatal side.”¹⁰

Alex Dlugi, National Medical Director, Infertility, Optum

MISCONCEPTION

Fertility benefits are not affordable for businesses with fiscally tight budgets.

TRUTH

The scope of benefits offered can work within an employer’s budget. San Jose, California-based tech company Cisco Systems Inc., offers fertility benefits of \$15,000 lifetime maximum for medical treatment and \$10,000 for prescription drugs, simply because it’s “the right thing to do.”¹¹

Impacts of Fertility Benefits

Societal & Health

SOCIETAL

Achieving family-building goals increases morale and satisfaction. With treatment, patients can avoid the common experience of depression and anxiety. We also know employers offering benefits increase their competitiveness and have happier, healthier, more loyal employees. With optimal health, we have a stronger, more functional society.

HEALTH

Fertility insurance benefits enable patients to make healthcare decisions based on appropriate medical advice, not financial concerns, and transfer fewer embryos. Fewer high-risk pregnancies, preterm births, and use of neonatal intensive care units (NICU) result from fewer embryos transferred. Insurance benefits increase access of timely and appropriate healthcare which provides cost savings. The U.S. Centers for Disease Control and Prevention says the use of single embryo transfers can significantly reduce the risk of high-risk pregnancies and multiple births.^{12,13}

HEALTHCARE COSTS¹⁴

Associated with Multiple vs Singleton Pregnancies



WHAT DO NATIONAL INSURERS SAY?

Insurers such as Aetna and Optum support evidence-based infertility treatment utilizing elective single embryo transfers (eSET). The incentive of IVF with eSET or rapid progression to IVF with eSET is predicted to be the most cost-effective strategy for patients, employers, and insurers.¹⁵

INCLUDING FERTILITY BENEFITS VS NO FERTILITY HEALTH BENEFITS

WITHOUT BENEFITS

Depression and anxiety associated with untreated infertility¹⁶

Individuals save only for medical expenses

Stress on relationships with spouse, family and friends

Increased risk of complicated pregnancy and outcomes

Costs related to disabilities, occupational and physical therapies, surgeries, etc.

Patients transfer more embryos, which can result in multiple births^{17,18}

MENTAL HEALTH

HEALTH INSURANCE USE & PREMIUMS

FAMILY RELATIONSHIPS

HIGH-RISK PREGNANCIES

LONG-TERM CARE OF PREMATURE BABIES

MAKING MEDICAL DECISIONS

WITH BENEFITS

Achieving family-building goals increases morale and satisfaction

Financial flexibility to contribute to economy, establish 401Ks, retirement planning, etc.

Supportive relationships

Timely and appropriate healthcare optimizes health and cost outcomes

Premature related costs are dramatically reduced

Patients' healthcare decisions are based on appropriate medical advice, not financial concerns, and transfer fewer embryos¹⁹

Types of Fertility Laws

WHAT ARE THE BENEFITS OF FERTILITY INSURANCE LAWS?

State-based fertility insurance laws increase access to reproductive therapies and services by reducing the financial burden to patients seeking treatment.

TYPES OF FERTILITY LAWS²⁰

LAWS TO OFFER

Insurers are required to offer fertility benefits to employers, but employers may choose whether to add the benefit to the plan.

LAWS TO COVER

Insurers and employers are required to provide fertility health benefits.

FEDERAL & STATE LAWS

Employee Retirement Income Security Act (ERISA) decrees self-insured companies and small businesses are exempt from state fertility laws.

Employers can still provide benefits, and many do, because they see the value and affordability of fertility benefits for their employees.

FERTILITY INSURANCE LAWS ARE AFFORDABLE

States that review evidence from economic and medical research, as well as testimony of constituents, insurers, and employers, often conclude they can save costs and promote greater health and wellness for their citizens by supporting legislation for insurance benefits for the treatment of fertility and fertility preservation.

The Truth About Fertility & Healthcare Premiums

WILL IVF RAISE INSURANCE PREMIUM COSTS?

Any additional service or treatment is bound to have an impact on costs. However, the effect of infertility coverage on the premium cost, as a whole, is very insignificant. Comprehensive state mandate reviews show that the increase is less than 1% of the total premium cost.^{21, 22, 23}

COMPARISON OF FIVE STATES WITH FERTILITY CARE INSURANCE LAWS

STATE	INSURANCE COVERAGE	COST IMPACT
MASSACHUSETTS <i>Established in 1987</i> <i>Updated in 2010</i>	Diagnosis and treatment of infertility. Most insurers voluntarily offer fertility preservation.	<1% total premium cost (0.12%-0.95%)
CONNECTICUT <i>Established in 1989</i> <i>Updated in 2017</i>	Diagnosis and treatment of infertility, as well as fertility preservation.	<1% total premium cost (0.9%)
RHODE ISLAND <i>Established in 1989</i> <i>Updated in 2017</i>	Diagnosis and treatment of infertility, as well as fertility preservation.	<1% total premium cost (0.36%)
DELAWARE <i>Established in 2018</i>	Diagnosis and treatment of infertility, as well as fertility preservation.	1% total premium cost
NEW YORK <i>Established in 2019</i>	Diagnosis and treatment of infertility, as well as fertility preservation.	1% total premium cost

What Can I Do?

Summary of What Legislators, Insurers and Employers Can Do

UTILIZE EVIDENCE-BASED DATA

All policymakers (legislators, insurers, and employers) make healthcare related decisions based on facts and information available to them. *The Policymaker's Guide for Fertility Health Benefits* serves as a tool to communicate the advantages of fertility benefits and point out the dangers and high costs associated with a lack of insurance coverage.

Without fertility benefits, our outcome costs are higher and health is at greater risk.

HERE'S HOW YOU CAN MAKE A DIFFERENCE

✔ ACCEPT

Realize fertility benefits provide access to affordable healthcare to optimize safe medical care and outcomes.

✔ ADAPT

Change policies to create a win-win environment for individuals, employers, and insurers.

✔ ACT

Implement fertility benefits to better the lives of the individuals you serve and directly reduce health disparity within the United States.

What Can Legislators Do?

UNDERSTAND HOW INFERTILITY IMPACTS CONSTITUENTS

Be aware of your constituents' needs, and consider their stories when you make healthcare policy decisions.

GAIN INFORMATION FROM EXPERTS

When relying on resources to understand fertility treatment, defer to specialists in the field of reproductive endocrinology to learn more about definitions, causes, procedures, and outcomes. The most accurate cost analyses come from states with existing fertility care insurance laws.

BECOME A CHAMPION FOR THE CAUSE

Defend the rights of infertile patients by opposing bills that prohibit the practice or funding of fertility treatment.

PROTECT YOUR CONSTITUENTS

Protect the rights of patients seeking insurance coverage for fertility treatment, regardless of race, gender, income, or sexual orientation.

GOVERNMENT TESTIMONIAL

“By lifting barriers to insurance coverage, we will ensure safe and affordable access to in vitro fertilization and help New Yorkers have better control over their reproductive health and family planning.”

Andrew M. Cuomo
Governor of New York

BACK EXISTING OR NEW BILLS THAT SUPPORT COVERAGE

Share this knowledge with other legislators who can sponsor or support fertility benefit bills.

What Can Insurers Do?

RECOGNIZE THE AFFORDABILITY OF COVERAGE

Recognize the affordability and value of including fertility benefits in insurance plans and support their inclusion.

SHARE COSTS

Make public data pertaining to usage of benefits and premium costs to enable employers and legislators to understand fiscal impacts on your state.

OFFER BENEFITS

Offer fertility benefits in small-business health plans and an option available for purchase by employers.

CREATE A RIDER POLICY

Allow employees to purchase, in addition to their standard health plan, a rider policy with fertility benefits.

MEDICAL GUIDELINE CRITERIA

By developing criteria which follow current medical guidelines established by medical organizations such as the American Society for Reproductive Medicine, you are providing timely and appropriate healthcare and minimizing the use of assisted reproductive technologies, such as IVF.

CONTROL COSTS WHILE OPTIMIZING HEALTH OUTCOMES

Providing benefits can reduce costs related to high-risk pregnancy, premature birth, and other associated expenses.

INSURER TESTIMONIAL

“It’s important for employers and health plans to connect the dots between the cost of the infertility benefit and the significant savings on the maternity and neonatal side.”

Alex Dlugi

National Medical Director, Infertility
at *Optum*

What Can Employers Do?

UNDERSTANDING YOUR EMPLOYEES' RIGHTS

U.S. and district courts have ruled infertility patients are entitled to protections under The Americans with Disabilities Act and The Family Medical Leave Act. Employees able to demonstrate a medical need to take time off to treat their infertility, or that of his or her spouse, have the right to such accommodations.

VERIFY INFORMATION

Insurance brokers may lack accurate data, such as how much an IVF cycle costs. Confirming facts with organizations like Fertility Within Reach will ensure informed decisions are made.

OFFER FERTILITY BENEFITS FOR A COMPETITIVE ADVANTAGE

With fertility benefits, you stay competitive in recruitment efforts while supporting your employees as they become parents.

EMPLOYER TESTIMONIAL

“By and large, [most of our employees] are starting to build their families and buy homes, and so that has driven the kinds of benefits we offer. We wanted to expand our offering to include employees that had experienced fertility challenges....”

Cathy Donahoe
Vice President of Human Resources
at *Domo, Inc.*

SHOW YOU CARE ABOUT YOUR EMPLOYEES' HAPPINESS AND WELLBEING

Providing fertility coverage can help improve your employees work ethic and secure their loyalty.

ADD FERTILITY BENEFITS TO YOUR EXISTING POLICY

If you use a brokerage firm to select health plans, request options you can extend during open enrollment. If you are provided plans with high-cost fertility and IVF benefits, ask the brokerage firm to find other choices. Affordable healthcare policies, which include fertility and IVF benefits, exist. Follow-up to determine how you can access them.

ARRANGE FOR OPTIONS

To balance competitive benefits with affordable options, arrange for more than one health plan to be offered to your employees. One plan could contain coverage for fertility, including IVF and medication benefits, and another plan could cover basic fertility, without IVF benefits.



Benefit Plans & Recommendations

SAMPLE COMPREHENSIVE EMPLOYEE BENEFIT PLANS

AMERICAN EXPRESS COMPANY	MASSACHUSETTS GENERAL HOSPITAL	EXCEPTIONAL SOFTWARE STRATEGIES, INC.
Not subject to infertility laws	Not subject to infertility laws	Subject to infertility laws
U.S. Headquarters: New York, NY	U.S. Headquarters: Boston, MA	U.S. Headquarters: Linthicum, MD
Industry: Financial Services	Industry: Healthcare	Industry: Information Technology
U.S. Employees: 55,000	U.S. Employees: 20,000	U.S. Employees: 110
Fertility Benefits: \$35,000 for full-time and part-time employees	Fertility Benefits: No limit on the number of IVF cycles, plus unlimited prescription fertility drugs for approved cycles	Fertility Benefits: \$100,000 for treatments: 3 IUI and 3 IVF cycles maximum per live birth (treatment cycles available to reset after each live birth) and fertility preservation

RECOMMENDED COMPONENTS OF A COMPREHENSIVE BENEFIT PLAN

- The scope of coverage includes the diagnosis of infertility, fertility care (such as IVF) and fertility preservation.
- IVF to be offered to those with medical need, as determined by a reproductive endocrinologist.
- To reduce healthcare disparity among employees, provide benefits, in terms of number of IVF cycles, instead of dollar limitations. Depending on individual treatment needs, some will utilize more dollars per cycle than others.
- Offer a minimum of four IVF cycles to help alleviate financial desperation when going through IVF, resulting in treatment decisions based on medical recommendations over financial concerns.
- Medication is part of the treatment protocol and needs to be included with benefits.
- Coverage for genetic testing can help reduce the number of IVF cycles utilized and minimize costs associated with miscarriage and genetic disorders.

Acknowledgments

Wisdom from Industry Leaders

Content within this guide is evidence-based. This tool provides credible information by utilizing the knowledge and guidance of medical doctors, attorneys, health communication professionals, as well as testimony from policymakers and patients. We are grateful for the contribution of these industry leaders.

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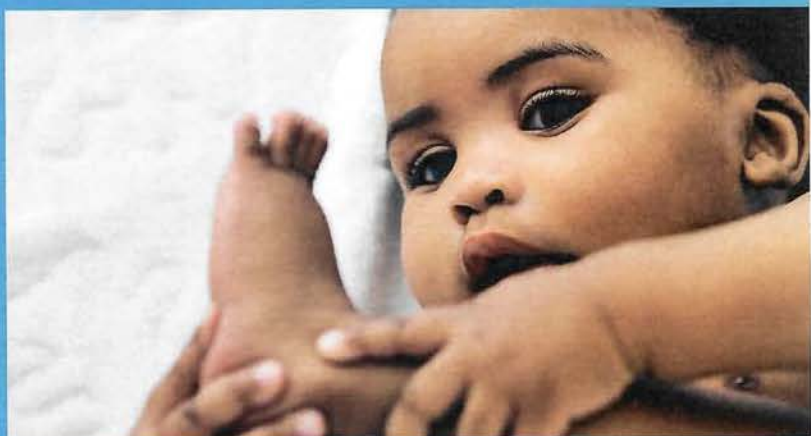
“Providing fertility health benefits is about offering timely and appropriate health care to increase the number of safe pregnancies and healthy babies.”

Davina Fankhauser
Co-Founder, Fertility Within Reach

References

1. U.S. Department of Health and Human Services, Office on Women's Health. Frequently Asked Questions. Infertility. 2009. <http://www.womenshealth.gov/publications/our-publications/fact-sheet/infertility.pdf>
2. Thoma ME, McLain AC, Louis JF, et al. Prevalence of infertility in the US as estimated by the current duration approach and a traditional constructed approach. *Fertility and Sterility*. 2013;99(5):1324-1331.
3. Chandra, A., Copen, C.E., & Stephen, E.H. (2013). Infertility and Impaired Fecundity in the United States, 1982-2010: Data From the National Survey of Family Growth. *National Health Statistics Reports*, 67, 1-19. Retrieved February 7, 2018, from <https://www.cdc.gov/nchs/data/nhsr/nhsr067.pdf> (PDF – 328 KB)
4. Macaluso, M, Write-Schnapp, TJ, Chandra A, et al. A public health focus on infertility prevention, detection and management. *Fertility and Sterility*. 2008;93(1):16.e1-16.e10.
5. American Society for Reproductive Medicine. 2015 Causes of infertility. http://www.asrm.org/Infographic_Causes_of_Infertility.
6. US Department of Health and Human Services. (2017) What is Fertility Preservation? <https://www.nichd.nih.gov/health/topics/infertility/conditioninfo/fertilitypreservation>
7. Chasse, J. 2018. Fiscal and Policy Note HB 908. Department of Legislative Services, Maryland General Assembly. P3. http://mgaleg.maryland.gov/2018RS/fnotes/bil_0008/hb0908.pdf
8. California Health Benefits Review Program (CHBRP). (2017). Analysis of Senate Bill 172: Fertility Preservation. Report to the 2017-2018 California State Legislature. Oakland, CA: CHBRP.
9. Aetna. 2015. Helping increase your chances of a safe, healthy birth. P3. https://www.ih-aetna.com/fcps/application/files/3515/0514/6746/Infertility_Member_Flyer.pdf
10. OPTUM. Infertility: Advances in evidence-based research for consumers, payers and employers. 2015. White paper. https://www.optum.com/content/dam/optum/resources/whitePapers/72815_Infertility_WP.pdf.
11. Livingston, S. 2016. Fertility treatment costs scare off employers. *Business Insurance*. P1. <https://www.businessinsurance.com/article/20160117/NEWS03/160119856/Fertility-treatment-costs-scare-off-employers,-but-those-who-offer-coverage-to-e>
12. Kissin DM, Kulkarni AD, Mneimneh A, et al. Embryo transfer practices and multiple births resulting from assisted reproductive technology. An opportunity for prevention. *Fertility and Sterility*. 2015;103(4):954-9611.
13. Center for Disease Control and Prevention. Assisted Reproductive Technology Surveillance, United States, 2010. 2013. *Surveillance Summaries*;62(9). Atlanta, GA: US Department of Health and Human Services.
14. Lemos EV, Zhang D, Van Voorhis BJ, et al. Healthcare expenses associated with multiple vs singleton pregnancies in the United States. *Am J Obstet Gynecol*. 2013;209:586.e1-11.
15. Karvir HV, Elashoff M, Miller BT, et al. Rapid progression to IVF with single embryo transfer as the standard of care for infertility: Results from a multi-center cost-effectiveness study. *Fertility and Sterility*. 2015;103(2):e26
16. Cousineau TM, Domar AD. Psychological Impact of Infertility. *Best Pract Res Clin Obstet Gynaecol*. 2007;21(2):293-308.
17. Jain T, Harlow BL, Hornstein MD. Insurance coverage and outcomes of in vitro fertilization. *New England Journal of Medicine*. 2002;347(9):661–666
18. Jungheim, ES, Leung, MY; Macones, GA; Odem, RR; Pollack, LM; Hamilton, BH. In Vitro Fertilization Insurance Coverage and Chances of a Live Birth. *JAMA (American Medical Association)*. 2017; 317(12):1273-1275.
19. Reynolds MA, Schieve LA, Jeng G, et al. Does insurance coverage decrease the risk for multiple births associated with assisted reproductive technology? *Fertility and Sterility*. 2008;80(1):16-23.
20. Kaiser Family Foundation. Mandated Coverage of Infertility Treatment. 2015. <https://www.kff.org/womens-health-policy/state-indicator/infertility-coverage/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
21. Compass Health Analytics. State mandated health insurance benefits and health insurance cost in Massachusetts. 2013. <http://www.mass.gov/chia/docs/r/pubs/13/comprehensive-mandate-review-report-2013-1-10.pdf>
22. University of Connecticut. Center for Public Health and Health Policy. General overview Connecticut mandated health insurance benefits review 2010. 2011. http://www.ct.gov/cid/lib/cid/2010_CT_Mandated_Health_Insurance_Benefits_Reviews_-_General_Overview.pdf
23. Well, K. Office of the Health Insurance Commissioner. Essential Health Benefits in Rhode Island. 2012. http://www.healthcare.ri.gov/documents/Essential%20Health%20Benefits%20Report%20to%20HIC_rfs.pdf

Fertility Within Reach encourages any person seeking additional information regarding legal protection related to family building to speak with an attorney in the field of Assisted Reproductive Technology law to determine how the courts apply related rulings in your state.



“ When my husband and I think of moving, for our careers, we now include states offering infertility laws in one of our determinants. We would not have our son had it not been for Illinois’ state infertility benefit law.”

REGINA TOWNSEND
Resident of Oak Park, Illinois

About



Fertility Within Reach

is a 501(c)(3) educational resource increasing access to fertility treatment and benefits through personalized consultations, workshops and legislative testimonies.



Fertility Within Reach.
ADVOCATING FOR FERTILITY HEALTH BENEFITS

1005 Boylston Street, #332 • Newton Highlands, MA 02461
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January 4, 2021

To whom it may concern:

One of my biggest dreams and wants in life was to become a mommy. Back in 2004 I was diagnosed with PCOS and was told that I would have to undergo infertility treatments in order to even have a slight chance at conceiving. This devastating news crushed my soul.

When spending days on end arguing with my insurance company on what procedures would be covered and not covered I had come to the conclusion that we just either take on the huge financial burden we will encounter or we just simply don't try to have a family. Well, I'm not a quitter so we decided to go for it. We spent 4 years trying to conceive which brought a lot of doctoring and a huge financial strain on us. We had maxed numerous credit cards and were looking at bankruptcy which terrified me. We were at a point where it was hard to make a living. So we decided to see a financial advisor. We were in deep debt and needed help. They were able to help us set up payment plans which took us over 7 years to pay back.

Through it all it was a very hard and emotional time in my life and I feel no one should have to feel the financial burden of infertility or to feel that barrier between wanting to start a family and infertility costs not paid by insurance. Couples should not have to have financial implications combined with a race against time.

Today I am blessed and thank God for allowing me to be a mommy to 3 beautiful healthy children.

Please support insurance companies in providing coverage for infertility.

Thank you,

Sherrece Golz

District 28

My husband Blake and I were married in 2009. We were actually afraid of getting pregnant right away and wanted to enjoy married life for a while before having children. That idea seems far from our reality now, like a dream; in the sense that dreams usually never manifest. Like a child, dreaming of living in a castle, or dreaming of being able to fly, or dreaming of a world without pain and suffering. Those events simply don't happen. That's what makes them a dream. For us, having children has become one of those dreams.

We've just passed the 7 year marker of "how long have you been trying to conceive?" The Josalyn you would meet today would be unrecognizable by the Josalyn of seven years ago. I've read in various places that the stress and grief of infertility is like that of going through cancer. Well I've never had cancer, but I do know that I wouldn't wish this battle on anyone. It is hands down the hardest reality of life that I've ever faced. It has challenged every belief I thought I had. It has rocked my marriage, my relationships with others, perspectives on life, love, grief, trauma, God, purpose, justice, fairness, faith; and mostly the perception of who I am and what value I bring to the world as a woman. I have experienced depths of depression that prompted me to tell my husband he needed to hide our guns. It's been ugly. It's been devastating. But most of all and worst of all has been the isolation and loneliness. From that place I've experienced a level of despair that only those that have experienced infertility can know. Despair that NO ONE should know.

I could write a book detailing the steps we've taken to have a baby. When we first started this journey, I was thrilled by the financial benefits our insurance offered regarding infertility. Unfortunately I was naïve at that time. I had no idea what was to come. We were frequently reassured by the medical world that we were "still young," that we just needed "a little help," and that "you'll be pregnant in no time." Treatments would surely work. Until they didn't.

Now, when I think about what monetary help we had from our insurance for infertility treatment, I just laugh. It is a spit in the bucket to what we've paid out of pocket to this point. Everyone assumes that it'll take just one or two attempts before success. In some cases that is true. Many cases it's not. For us, it has taken 9 attempts (and counting) and, all the while being told that everything looks great, it's just bad luck. It took that long before we were told I likely couldn't carry. Up until that point, I outperformed in many of the lab tests and other requirements needed to conceive. "Your uterine lining is perfect, your hormone levels are perfect", I was told. We were also told that "your embryos are perfect." My point is, sometimes it takes multiple tries to even figure out what the issue is. Infertility is a MEDICAL problem. Just like cancer is, like diabetes is. Would we tell someone who has cancer to "just relax, it'll resolve", or not offer someone medications to treat diabetes? That answer is obvious. And yet, infertility has not been viewed as a medical problem that requires treatment. Infertility has been treated like an elective problem.

We have spent well **over \$150,000 out of pocket** to start our family, and still do not have a baby. We currently have **an \$85,000 loan outstanding**. This has significantly impacted how we live now and will continue to impact our lives years from now, whether or not we are successful in our endeavors to have children. No matter what route a family chooses in efforts to have

children, whether that be adoption, infertility treatments or gestational surrogacy, NONE of those options are cheap, and none of them are easy. Some may ask, “why wouldn’t you just quit, or why would you spend that much money?” Children are priceless, and that is why intended parents would, and often do, spend their life savings to experience the joy of parenthood. But that certainly doesn’t mean that they should.

Josalyn Grueneich
Fargo, ND District 16

Dear Committee Members,

Going through infertility without insurance help has been the most stressful, hardest thing I have ever had to do. We, my husband and I, have ever had to do – emotionally, spiritually, physically, financially. Over roughly three years, we spent around \$10,000 to try medications, testing, having HSGs and ultrasounds, three rounds of IUI, all of which were unsuccessful. We then spent nearly \$30,000 out of pocket to be on the “VIP” program through the Midwest Center for Reproductive Health for IFV. Approximately 20,000 of that was for the actual procedures while over \$8,000 was spent on my medications.

Since we had recently purchased a home, we were unable to take out any personal loans to help with our dream of having a child. We had used up all of our savings over the first two years to unsuccessfully have a child... the out of pocket costs for being “infertile” are so high. The ultrasounds for over \$200 each that you HAVE to get to check to see if your IUI works... the medications, checking to see if you have PCOS and all that goes along with that diagnoses, the office visits... all out of pocket with no help from your insurance. We had to rely on our parents to continue our journey with IVF. Luckily, thankfully, both of our parents were able to GIFT us money to help with IVF.

After then becoming pregnant and giving birth to two baby boys, our financial problems didn't just go away. Both of them ended up having surgery within the first three months of life, in August of 2018 – one of them undergoing an upper-lobectomy to have his lung lobe removed at Minneapolis Children's. These costs just added up on top of the ever-mounting out of pocket costs we had already incurred.

Not only is this financially draining, but ask yourself what type of strain you think it would put on a marriage. To know intercourse is no longer something you do out of love but something you put on a schedule so that your medications line up with a deadline and a goal in mind. To lose the passion and have intercourse become a job. To have the financial strain on every single other aspect of your marriage because while you are trying to have a child, you cant afford anything else. To have the emotional roller-coaster of the ups and downs of having hopes and constant disappointments. One after the other, month after month. The emotions of the medications. The emotions of defeat and despair. To spiritually wonder if the God, your God, that you pray to - listens. To test your spirituality day after day, month after month. Year after year.

Please support this bill so that other families, like me have this chance to build their families. They have already went through so much to have their dream of having a child put on hold, possibly forever, they should not have to deal with the financial burden as well.

Lindsey Hefta

District 8

Dear Committee Members,

I never thought in a million years that I would have a “fertility journey” to share. I want to share the short version of the journey. So, long story short, I started with my infertility journey in 2013, when my husband and I were not getting pregnant. We lived in Beach, ND then, and would have to drive to Williston (100 miles one way) to meet with my amazing doctor (Dr. Beverly Tong) at the fertility clinic there. She started me off with some tests. After those, she decided to start me on Clomid. She was going to try this for 3 months but, unfortunately, my husband passed away on our second month of being on Clomid. I was devastated and torn to whether wanting to be pregnant and having a piece of him with me but, also having to raise a child alone. I ended up not being pregnant, unfortunately.

Fast forward, I needed to get away from everything that happened so, I applied for a job and was moved to Ashley, ND. After being in Ashley for a little bit, I ended up pregnant, with my now husband, Barrett Herr. This was a complete shock to us. I honestly didn't think I could get pregnant but, that is something that after trying for so long, you start telling yourself.

About 1 year after he was born, we surprisingly ended up pregnant again. I was shocked and had a lot of hormonal thoughts going on in my head. Our little guy ended up in the NICU at about 4 days old. He didn't sleep through the night and we were going through some health issues with him: lots of ear infections, on a nebulizer from the start of 5 months old, etc. I cried when I found out we were pregnant again. I didn't know how we would handle another child. I started bleeding around 7 weeks and even though we heard the heartbeat, I did miscarry. Every day since, I've regretted being so sour about becoming pregnant again. If you have experienced a miscarriage, you know the horrible feeling of birthdays, due date, seeing other little kids run around that are the same age that yours would have been. It is truly horrible, and I wouldn't wish it on anyone.

Fast forward to now, we haven't been pregnant since. We have tried and tried. We wanted to be proactive and realize that since I already had issues prior, that we wanted to get to the bottom of the cause of the infertility. Since we live in Wishek now, the closest fertility clinic is Fargo, ND (178 miles one way). We started seeing them and since, have done medicated timed cycles and IUIs, all failing. Our official diagnosis is “unexplained secondary infertility.” Our next step was IVF. We had no intention of doing IVF when we started. We said, if it gets to that point, we will just adopt instead. We had many deep, in-depth conversations about if we should or shouldn't do IVF. From the beginning, we knew our insurance would cover NOTHING since, it hadn't covered anything since we started. The cost is huge and that was part of the reason we said we'd rather put that money into adoption, especially when IVF is not guaranteed.

We decided we would give IVF a shot. If this didn't work, we would then adopt. We wanted to make sure we explored all options before “giving up.” We did end up with 6 embryos, that were genetically tested. The genetic testing was an extra cost of around \$4-5,000. However, we knew it was important to do and we decided to go ahead with that testing. We do know, based on genetic testing, that we have 4 boys and 2 girls. If all goes as we hope, we will eventually donate our remaining embryos. We want to be able to give the gift of being a parent to all who hope to.

Our transfer date was set for April 9th but, with the corona virus pandemic, it has been postponed. We now have our daughter in our arms after one of the most mentally and physically exhausting journeys to parenthood. My wish is others do not have to go through the financial barriers we did in order to receive this blessing.

-Patti and Barrett Herr

District 28

Chairmain Lefor and Committee,

We would like to be open and vulnerable about a challenge we are experiencing, it is a story we only share with our close family and a few friends, and a few others know about our challenge but not the details or what the experience is like. Although you can't see our struggle from the outside in our hearts we feel a missing piece. Despite our efforts we have yet to be able to expand our family. There has been much hurt and pain in our hearts as we align to overcome our fertility challenges. The fertility journey has been long, lonely, disappointing and so many other hard emotions. In my heart I know we have children waiting to join our family, but they seem just out of reach. And yet we remain hopeful and hold a knowing in my heart I'm meant to be a mom.

I know a bill can not magically make me pregnant or the 1 in 8 other couples struggling to get pregnant. However you can help support us and maybe that helps us get pregnant.

Robin Holt

Grafton, ND

Lucky #7



“When are you having kids?!” “You're not getting any younger!” “Don't you want kids?” The typical questions when you get married but what people didn't know is that it wasn't that easy!

I was diagnosed with PCOS when I was 29. I had major hair loss which led me to get my hormone levels checked. I found out that my DHEA level was 3x higher than a normal female and I was told that it was going to be hard for me to get pregnant.

Dustin and I decided to not worry about it at that time, we were newly engaged and we will figure it out when or if something happens. We got married on June 6th, 2015 and after the honeymoon in October, we decided to try and start our family. In November 2015, we got pregnant for the first time! Since I knew that my hormone levels were a little off, I called my NP and asked if there were any medications that I needed to take. She said no and we made our first appt to check the baby at 12 weeks. At 7 weeks pregnant, we had our first miscarriage at home. We never thought it would happen to us. We were told it would be hard to get pregnant, not stay pregnant.

We took some time to heal from our loss. Then July 2016, we got pregnant for the second time. Everything was going great. I was feeling good and I had a 10 week ultrasound scheduled since I had a prior loss. We went to our appt. excited to see our little baby. As I was laying there, the ultrasound tech said this is the baby but there is no heartbeat. We were devastated. We had no reason to think this would happen to us again. The doctor came in and confirmed that the baby did pass away and only measured 7 weeks. I chose to do a dilation & curettage, which is a procedure to remove tissue from the uterus, to test the tissue sample from the baby on why we lost yet another baby. Results came back that our baby girl had a chromosome 4 abnormality.

We were referred to the only Maternal Fetal Medicine doctor in North Dakota, Dr. Tobiasz. MFM doctors work with women who are considered to be high-risk pregnancies whether it's due to blood clotting disorders or genetic abnormalities and/or multiple other things. Since we had two previous miscarriages, one of them was due to a chromosomal abnormality and our age, we were now high-risk. After meeting with Dr. Tobiasz, we were scheduled to have genetic testing, which came back clear for both of us, as well as an antiphospholipid antibody test. To our surprise, Blue Cross Blue Shield denied to cover the cost of my appointment with Dr. Tobiasz and the antiphospholipid test. BCBS didn't feel it was necessary that I see a specialist at that time or that I needed the test. I contacted Dr. Tobiasz to see what could be done and she had to write an appeal on my behalf. I was referred due to infertility but it was not covered under the infertility coverage. The \$20,000 once in a lifetime infertility coverage from Blue Cross Blue Shield was harder to use than we thought and this was only the beginning of it.

November 2016, we were pregnant for the third time, hard to get excited but we had hope that this time was going to be different. Hope quickly faded when we had another miscarriage at home at 6 weeks. We didn't know if we could do this again. Everyone around us was getting pregnant with ease and still the questions of 'when are you having kids?' was still being asked.

May 2017, pregnant for the fourth time. I made an appt for blood work and ultrasound. I was 5 weeks pregnant and HCG came back great. We finally got to see our little baby on ultrasound for the first time too. It was tears of joy this time! Heartbeat was good but I went back the following two weeks to make sure the baby was getting stronger. Staying positive I went in for our third ultrasound, our baby no longer had a heartbeat. We were devastated. Why was this happening to us again? What was I doing to cause my babies to leave us so soon? I was on progesterone medication to help with the pregnancy but still couldn't keep our baby safe. No one had answers for us. I was then referred to a reproductive endocrinologist.

We thought about it for a while and decided it wouldn't hurt to go talk with a RE and see what they would have to say about our infertility and chances of starting a family. We were referred to Dr. Corfman from Midwest Center of Reproductive Health. After doing our research on Dr. Corfman, we knew we would be in great hands. MCRH has a great reputation and his success rates are consistently amongst the highest in the nation. If we were going to have to do any infertility treatment, I wanted the best. We only had the \$20,000 once in a lifetime limit from BCBS, so we thought.

January 2018 we met with Dr. Corfman. After going through all my blood work and history, he felt like starting letrozole medication would help us achieve a healthy pregnancy. I would get an ultrasound on day 1-3 of my menstrual cycle to make sure I didn't have any cysts on my ovaries. If everything looked good, I would start letrozole medication on day 3. Day 10 of my cycle, I would get another ultrasound to see how many eggs were mature. Depending on the number of eggs matured, I would give myself an injection to make me ovulate then we were able to try to conceive at home. First cycle was cancelled due to too many eggs being mature. We were nervous that if too many eggs would fertilize that there could possibly come with other complications. We were hopeful since it worked so well that we would have success in the next

cycle. Second cycle was cancelled due to a cyst on my ovary so I went on birth control for the rest of the month. Third cycle we had 3 mature eggs and we were finally able to try but were not successful at getting pregnant. Fourth time was cancelled again for a cyst on my ovary and back on birth control. It was exhausting! We decided to just take a break from everything. It was beginning to be too much emotionally and physically. With all the ultrasounds and medications, the staff had to be sure to use the correct ICD-10 diagnosis codes to make sure insurance would help cover it. The diagnosis of "infertility", ICD-10 N97.9, didn't mean that it would actually be covered under the \$20,000 infertility BCBS has and it didn't. Cycle after cycle the bills were rolling in. There was an excuse every time I called BCBS to see why the infertility coverage wasn't being used.

After taking a much needed break, November 2018 we were pregnant for the fifth time and again ended with heartbreak at 6 weeks. We met with Dr. Corman in January 2019 again to go over our options since the additional miscarriage. We discussed IVF, IVF with PGS (pre-implantation genetic screening), IVF with egg donation and/or sperm donation, embryo adoption, continuing letrozole treatments, and adoption. We always had the questions of what if? What if we fail with IVF? We felt like we needed to try one more thing before we would start applying for adoption. We decided to proceed with IVF. I first needed to get a uterine fibroid removed that I was diagnosed in years earlier. The fibroid was pedunculated, meaning it was located on the outside of my uterus held on by a stem. Having the fibroid located on the outside of my uterus, my OBGYN didn't feel it was the cause of my miscarriages but Dr. Corfman didn't want anything in the way of having a great chance of having a successful pregnancy.

We started our IVF process in May 2019. Midwest Center of Reproductive Health pre authorized all procedures/medications with my insurance and we were DENIED 100%!! This was a huge shocker to us. I was told by my insurance to try for another year and/or due three IUI's due to having the fibroid removed. I had doctors write appeals to BCBS saying that IVF is the best option for us but we were still denied. Being 35 years old at this time and already went through three and half years of struggle, we didn't want to wait any longer. We didn't need the help at getting pregnant, we needed the help staying pregnant. The control that IVF has was what we needed. It helps align all the hormones you need to help get and stay pregnant. It's not a guarantee but it was worth a shot. It was a big decision financially but we decided to proceed with IVF anyway. We also chose not to do PGS (pre-implantation genetic screening) due out of pocket cost of IVF.

The total cost with IVF was a little over \$20,000 out of pocket. \$11,295 to MCRH, around \$6,000 for medications and procedures, ICSI \$1,940 (the process of them inserting the sperm inside the egg, this gives a better chance of fertilization) Embryo freezing \$1000.

After all the injections and ultrasounds, it was time to head to Minnesota for our egg retrieval. We were successful at getting 21 eggs retrieved , 17 eggs were mature, 14 eggs were fertilized and we had 10 embryos on day 5. We transferred 2 embryos on day 5. We got a call the next day saying that only one embryo made it to day 6 and is now frozen for future use. Now the two week wait began to see if the embryos implanted and if we were pregnant.

The two weeks seemed to creep by but it was time to get my blood draw to check my HCG levels. They were outstanding! I needed to go back in two days to make sure the levels doubled but they actually tripled. With the HCG being that high, it was an indication that both embryos implanted and we were going to have twins. We were not getting our hopes up again like the previous 5 times but this time felt different. But at 6 weeks again, I started to bleed. I felt like my world was crumbling. Crying hysterically, I woke up Dustin and told him that it was all happening again. I had to wait a couple hours until Dr. Corfman's office was open to call them and let them know what was happening. They told me that I still needed to wait another week before getting an ultrasound. This was due to being so early in the pregnancy and possibly not being able to see development on ultrasound at that time. The week-long wait was miserable.

It was time to go for the ultrasound. We could finally breathe when we got to see one little baby and it's heartbeat! Since we were on different medications this time, we were cautiously optimistic that it was going to work this time.

Being pregnant at 35 years old, you are considered advanced maternal age and high risk. They asked if we wanted to get the blood test to see if the baby had any chromosome abnormalities. They take a blood sample from me and separate the baby's blood to look at the baby's DNA. The results were back in two weeks. We got the call from my doctor saying that there was a chromosome abnormality in our baby. We were told that we were having a baby girl and that she was missing the whole X chromosome. She was going to have Turner syndrome. Not knowing what this even meant, we did some research. With all the possible conditions that Turner Syndrome patients can have, not being able to conceive children is what hurt us the most. I didn't want our child to go through the heartache that we experienced but we would give her the best life we could possibly give.

We were scheduled to go see Dr. Tobiasz again and a genetic counselor to talk about our future. The genetic counselor told us more about Turner Syndrome and what to expect. She explained to us that this is a somewhat common chromosome abnormality. The pregnancy ends in an early miscarriage normally when there is a whole deletion of this chromosome and so you don't even know your baby had it. Our baby was a little fighter for sure but we weren't out of the woods yet.

Dr. Tobiasz asked if we were wanting to do an amniocentesis to confirm that our baby had a chromosome abnormality. The amniocentesis would take the cells of the baby from the amniotic fluid and check the baby's DNA. We decided to proceed but with this procedure comes other risks. The procedure took about 20 minutes total and then we were to wait for the results.

Results are in!! Baby girl is 100% chromosomal normal. There are no abnormalities whatsoever. After talking with Dr. Tobiasz, we told her about our IVF process. We told her about transferring two embryos and spotting at 6 weeks. I felt like a lightbulb just went off. She couldn't 100% confirm but it is all linking up to the other embryo that was transferred during IVF was the one that had Turner syndrome. This is why I had my 6th miscarriage at 6 weeks. Both embryos had

implanted, both of their genetic makeup was within my blood when they did the blood test to check for chromosome abnormalities. The test had picked up the genetic makeup of the baby that we miscarried. We would have had twin girls! Due to our history of miscarriages, if our IVF would have been covered by insurance, we would have gone through with the PGS (pre-implantation genetic screening) of the embryos to check for abnormalities. We were quoted that PGS may cost close to \$20,000 depending on how many embryos would be tested. IVF with PGS would be upwards towards \$40,000 and that was not something that we could manage to do. With PGS, we would have found out that our baby girl didn't have a great chance of survival and wouldn't of had to go through the heartache of having another miscarriage. Out of the \$20,000 infertility coverage from BCBS, I have used under \$2000 for my 4 years of infertility.

We are currently paying for storage of one embryo at \$400 per year. If we would decide to transfer the embryo it would cost \$8-9000, this would include the monitoring and medications needed. You find out the day of the transfer if the embryo survived the thawing process, so just like IVF, there is no guarantee that you will carry the pregnancy to term.

We received two refunds from BCBS. \$560.01 and \$280.00, for something that was done during the IVF process in May/June 2019, there was no explanation on the refund checks. We felt that we will take any refund we will get. Over one year later, in July 2020, we received a notice from BCBS saying that the refund was a mistake and I needed to issue them a check of those amounts. I contacted BCBS and asked why I even received a refund when it was all pre authorized and denied anyway. They had no answers for me and told me to appeal the claim if I would like. I had to appeal twice due to being denied the first time. Finally after explaining to them in great depth of my infertility journey, the claim was dismissed.

We still don't have an answer why we lost so many babies. Two of them were due to chromosome abnormalities but the doctors don't believe that was the case for the other four. This is something that we ask ourselves daily but we are extremely blessed and grateful for what we have today. Our beautiful baby girl was born on February 20, 2020. It may have taken us 4 years to get to this point with the help of IVF but we know that she was the right one for us.

She is our miracle baby, Lucky #7!



I am Paige Johnson, born and raised in North Dakota. I had always dreamed of becoming a mother someday. Once my husband and I started trying for a baby it came apparent that dream might be harder to accomplish than expected. I was diagnosed with PCOS, Endometriosis (which I had to have surgery to remove), and my husband has male factor infertility. After all the testing we were informed the likelihood of having children on our own would be slim. We contacted both our insurance companies to double check that we indeed did not have any coverage for infertility treatments. We decided we would try IUIs first since that was the "cheaper" route. We endured 4 failed IUIs and were left with only the hope of IVF to become parents. But how are we going to afford this? We were scrounging for money for the IUIs and that is a fraction of the cost of IVF! We had to have family members help us out with the IVF down payment and the rest of the costs we put on a payment plan. Adding the financial stress on top of the emotional, mental and physical pain you are already enduring is unbearable. We have a medical diagnosis and still don't qualify for any coverage?! We spent over \$37,000, grieved the loss of one of our twins, and were finally blessed with our daughter on December 27, 2016. The medical assistance of IVF made us parents. We NEED to have something in place that makes it more attainable for the MANY infertile couples in North Dakota to reach their dreams of becoming parents. Starting your family is suppose to be one of the most exciting times of your lives. When you have an infertility diagnosis and the extra financial stress that "exciting" time in your lives quickly becomes one of your lowest points. I think it is extremely important to provide coverage for the 1 in 6 couples in North Dakota that have no choice but to turn to doctors for help in conceiving. These aren't "elective" treatments. We have a very real medical diagnosis (from not just 1 doctor but 4!) that did not allow us to conceive without medical assistance, why should we be punished even more for that?

Thank you for your time,

Paige Johnson
1/2/2021
District 28

Committee Members,

I was diagnosed with polycystic ovary syndrome in January of my junior year of high school. I remember being at the clinic and my doctor telling me that I had PCOS, which potentially could affect my ability to have kids. Finding this out as a teenager was extremely difficult and life altering in an already emotional part of every girl's life. Suddenly, I began to worry about my infertility risks instead of concentrating on everyday parts of my life. Those first few weeks I couldn't focus at basketball practice, school, or even home because all I could think about was my diagnosis and my fertility rates, often I ended up crying myself to sleep or breaking down randomly. As my emotions continued, I would then begin thinking about the "why's". Why is my body like this? Why can't I be normal? Why can't my ovaries do the one thing they were made for? Why do I have to worry about infertility when no one else my age is even thinking about kids? These are questions that I still often ask myself, and while PCOS does increase infertility rates, a bill like this could greatly take the burden off of me and many other people who are going through what I am. Knowing that there are options and monetary support available for when the time is right to start a family of my own would have been huge in reducing the worry that I had to go through as a high school student. Recently I found out that none of the treatments for my PCOS have been successful and that my infertility rates are even higher than originally expected, and a bill like this could be the difference that gives me the chance to someday start my own family.

Kathleen Schmidt

NDSU College student

Hometown Ashley, ND. District 28

Dear Committee Members and Legislators,

Our infertility journey started in 2013. At this time we weren't trying and we got pregnant! We were thrilled but a couple months into the pregnancy, we lost our baby at 10 weeks. We decided to wait awhile and then when we started trying actively again, months went by and nothing. A year into it we meant with my OB and discussed testing to see if there was anything going on with either of us.

I was diagnosed with unexplained infertility at that time. Shortly after we started trying IUIs. We would do one IUI and then take a month or two off and did that for about a year. We then pursued trying on our own again. The constant appointments and the medications become so costly and really take a toll on your body and mental health. I tried to be patient and give my body breaks during the process. Each time became more devastating than the last time. To take numerous pregnancy tests and only see one line, it is heart wrenching.

We continued to do this process for a few years, do an IUI or two and then take a break. This went on until December of 2019, 6 years from the time we lost our baby. At this point we meant a second time with a doctor to discuss IVF. The first time was 3 years prior and the expense was just too great to move forward. After our consultation we started planning, calling to see what my insurance would cover, and figure out financially if we could take on the cost. We also found out I had a polyp in the process and had to have that surgically removed in February of 2020. Ready to go at this point!

We were thrilled when my insurance told me they would cover 80% of the cost. We decided to move forward and started the medicine for an egg retrieval in late May. We made the trip, the very uncomfortable trip for me, to MN for our egg retrieval. They retrieved 19 and 16 made it! By day 5 we had 3 healthy embryos and by day 6 we got 4 more! These are amazing results! So on June 4th we did a fresh transfer with 2 of our embryos. The rest went off to a facility and will sit frozen until or if we chose to try again. Then the 2 week wait came. Unfortunately, IVF did not work. The doctor assumes either the embryos weren't healthy or my estrogen was really high. We were beyond devastated as we most likely couldn't afford to do this again. A month later more bad news came. My insurance failed to tell me that I had an \$8,000.00 deductible that had to be met before they covered 80%. This was a huge financial setback.

Fast forward to August, we fought my insurance company on the coverage and they reimbursed us the money they said they would cover in the beginning. So we were able to pay our past debt from the procedure but now what. We opted to set up a GoFundMe page and try to raise enough money to try again. We made enough for the down payment and started to get ready for a November Transfer. Again they found another polyp, so back in for surgery the beginning of October. During this time I was also fighting Covid-19. I made it through the surgery and we were scheduled for a Transfer November 4th. On October 30 it was cancelled. My fallopian tubes had filled with fluid in a short 6 days from my previous ultrasound. So back into surgery on December 3rd and still fighting Covid-19. Both of my tubes had to be removed, so now IVF is the only chance of having a baby. We were determined to do a 2nd transfer and pushed through all the obstacles and had our transfer on January 14th 2021! Currently we are waiting to see if we will get our miracle baby. Regardless, it is all in God's timing. We are blessed to have a second

chance at IVF and so thankful for the family and friend's that helped make that possible. So here is to everyone else waiting, may you someday get what your heart desires. God has a plan for all of us! Thank you for letting me share our story with you!

Emily Lewis
District 47

1/22/2021

Chairman and Committee,

My husband and I tried to have children shortly after we were married and began doctoring soon after. We were given a medical diagnosis of unexplained infertility and tried many invasive procedures that were emotionally and financially exhausting. I was lucky to have some insurance coverage but it was a lifetime maximum amount that was quickly spent after one IVF cycle. The cost to continue treatment was astronomical but we did not want to give up on our dream of having children. We had to stop treatments for long periods of time to save up what money we could, borrow money from family, and max out our credit cards. So on top of the mental and emotional anguish, we also had to deal with the stress of how we were going to pay for continued care and the never ending medical bills. The financial stress affected every aspect of my life; my job, my relationships with family and friends, and my relationship with my husband was strained not only because of the sad reality we were living every day but also because of the financial situation we were in. It took us almost seven years and over \$150,000 to finally welcome our son via gestational carrier. Infertility is a medical diagnosis I don't wish upon anyone. It's a long, lonely, and expensive process. Insurance coverage for an infertility diagnosis needs to be provided for everyone!

Kristin Natwick

4912 Cornice Dr,

Bismarck, ND 58503

It's surprising how much your arms can ache to hold your baby that doesn't even exist. It's torturous how infertility consumes you, on and off all day, every single day.

Not even two weeks after my husband and I got married, and at 32 years old, I was diagnosed with stage 2b triple-positive invasive ductal carcinoma. Instead of a honeymoon, we were looking at chemotherapy, surgery, radiation, and years of hormone-blocking therapy. Thus, the plans we had for our newlywed years, which was starting a family, were quickly replaced with the plan to simply stay alive.

Women under 40 can and do get breast cancer; chemo and radiation can and do cause damage to fertility. Modern medicine has made it possible for cancer survivors to go on to live long, healthy lives, but what happens when the life you are left with after cancer is nothing resembling the life you had planned? Survivorship is a necessary part of cancer care and fertility preservation before treatment needs to be at the forefront for patients who want a family.

Insurance denied our claim for embryo preservation before beginning treatment, despite the fact that I had fertility benefits through my employer, claiming it was "medically unnecessary" because I did not meet their criteria of trying to conceive unsuccessfully for two years in order to be considered infertile. Any oncologist will affirm that infertility or fertility complications are a frequent result of cancer treatments. Insurance is defined as "a thing providing protection against a possible eventuality." What else is infertility as a result of cancer treatments if not a possible eventuality of those treatments? Where is the protection provided to cancer patients for this possible eventuality?

Fertility preservation must be honored in the same regard as any other part of cancer care and insurance coverage must be standard.

Fortunately, my husband and I were able to do embryo preservation before I began chemotherapy, but only because family, friends, acquaintances, and even complete strangers rallied together and in less than 24 hours raised money for us to cover the cost. Not everyone is as fortunate. Crowdfunding should not be the expected or accepted financial plan for any medical expenses. Cancer patients and survivors will always have enough of a financial burden with the years of treatments, routine tests, medicines, therapies, and other expenses. Costs for fertility preservation and fertility treatments just add a cruel and unnecessary burden.

Two years after my diagnosis, my oncologist gave me her blessing to pause my hormone-blocking therapy to try and start our family and take part in a clinical trial that seeks to prove whether or not pausing hormone-blocking therapy to get pregnancy increases a woman's risk of recurrence of hormone positive breast cancer. We tried to conceive with the help of fertility treatments and wait to use the two embryos we had. For over a year, I felt like more of a lab rat than I did throughout all of my cancer treatment. At every visit where we tried something new, I was met with the same apologetic expression of pity from my fertility doctor saying my body wasn't responding. My ovaries appeared atrophied, my uterine lining was too thin to support a pregnancy, and my menstrual cycles had completely stopped since starting chemo. Attempting everything possible to get your body to perform its most biological function after beating cancer is a real slap in the face of your survival. You don't feel like you have survived. You feel like you have died.

Finally, after getting a second opinion with a fertility specialist at Mayo Clinic, we tried a more aggressive plan and my body's response was sufficient for a transfer of one of our two embryos. Against all odds, it resulted in our perfect, strong, healthy daughter, Lola, who is now 21 months old and the center of our universe. It's impossible to imagine our life without her, but

I cannot forget that she would not be here without the egg retrieval that happened just two days before I had my first chemotherapy infusion and that we couldn't afford on our own.

Fertility preservation matters. Insurance coverage of fertility preservation matters. Fertility preservation provides hope and insurance before, during, and after cancer. There is so much at stake for a cancer patient who hasn't started a family before cancer strikes. A cancer diagnosis is devastating enough. Knowing that the treatment might leave you infertile is heartbreaking. Not being able to do fertility preservation before beginning cancer treatment because it is not covered by insurance and too expensive simply should not happen to anyone. Fertility preservation must no longer be viewed as elective. It is medically necessary.

Tiffany Olsen
District 16

January 6, 2021

Re: Infertility Testimony

He's now 20 and a baseball player for Mayville State University. Did we ever think this day would come? The answer is no. Our son was born to two parents who were over the moon, not believing that what transpired before his birth would bring us such joy and unconditional love.

Married in 1990, we decided that two years later we were ready to start a family. We had teaching jobs, not a lot of money saved at that time, but a home that needed to be filled with children. Everything else seemed to be falling into place, so how hard would it be to get pregnant...

The answer was HARD! After months of trying, we decided that we needed to get some help. After months of help (Intrauterine inseminations, drugs, travel expenses, and disappointments), we decided to take a break. Financially we just couldn't swing it anymore, and the heartbreak each month brought frustration and a strain on our marriage. Then Don lost his father to cancer, and we just decided to give up.

Fast forward to 1999/2000...we decided to try again. It was now or never. We gave IUI four more tries, and by God's grace and money given to us by our families to support our dream, we found out in February 2000 that we were pregnant. Our son was born in October 2000. A blessing, but not an easy one. We only have one child, and we thank God every day for him. We couldn't do it again, to try for another. Financially it was impossible, though we so wanted a sibling for our son.

For those who endure the struggle of fertility, it is an emotional roller coaster for all involved. I look at our world today, see all the children who were born to those who really didn't want, or they can't take care of them, and it breaks my heart. If those individuals who are wanting, dreaming, hoping to have children, then why is it such a financial struggle. That's the bottom line.

I pray that soon something can be done to help those who deserve to have the title of Mom and Dad. Thank God that my husband and I have that title!

Sincerely,

Mary and Don Paulsrud

Ashley, North Dakota District 28

My name is Kaydee Pederson. I have a wonderful husband named Matthew. We've known each other for eleven years and have been married for four years with a cozy little home in Minot. Our household is full with two playful dogs and one princess of a cat. We are ready to begin the next phase in our life: starting a family.

Starting a family was never going to be easy for us however. I was diagnosed at birth with a genetic disorder called Turner Syndrome (TS). One common characteristic of TS, besides short stature, is infertility. TS can cause underdeveloped ovaries, premature ovarian failure, and diminished ovarian reserve. In simple medical terms, most women with Turner Syndrome are missing a vital part of the reproductive system: functioning ovaries and viable eggs.

It was never secret from me that because I have Turner Syndrome, having kids naturally was not going to be an option for me. Knowing this fact all my life does not make the heartache of infertility any easier. Every pregnancy announcement brings a tinge of jealousy. Each hug from my nieces and nephews makes my heart yearn for my own child to hold. I try to keep these feelings inside because it's not anyone's fault I have to take a different route toward family building. I was made this way for a reason.

My amazing and supportive mother and father kept my heart open about adoption being my future option to build my future family. To be perfectly honest, it never occurred to me until a few years ago there could be another path for me and my husband to take to grow our family that would allow my husband the chance to have a biological child.

Knowing we have a choice like IVF using the gift of egg donation gives me so much hope I didn't know I could have. I never dreamed it would be a possibility for me to ever experience being pregnant or childbirth. IVF with donor eggs allows me that chance. The fact that our future child, or children, will not share my DNA has never fazed me. DNA is just a blueprint. Donor egg or adoption, the child raised in our home will be loved, cherished, and most importantly, wanted.

Want and love however are sometimes not enough. Anyone experiencing infertility can tell you that. We have the science, medicine, and technology to do amazing things to help those affected by infertility, which is a medical condition. Cost should not be a factor in receiving care for treating a medical condition. Unfortunately, cost is the biggest factor in my husband and I moving forward with treatment at this point in time. We're saving all we can right now so we don't take on debt to make our dreams of a family a reality. It takes time to save, and frankly, after so many years of believing I had no route but adoption, I'm impatient.

I was born with underdeveloped ovaries and no eggs. In my case, nature literally said "No."

Science for years has been saying "Maybe."

I truly believe when my husband and I are able to move forward with treatment financially that God will say "Yes."

Dear Committee Members,

We were married July 30, 2010. We both knew we wanted to have children as soon as we possibly could. After a months of trying I asked my doctor what I could do. She said nothing, you're young and we ask that every couple try for at least 1 year before we evaluate anything. So, 365 days later, I was back in the doctor's office. This time, she agreed to have me do some testing. Sure enough I was diagnosed with Polycystic Ovarian Syndrome. They referred me to an "Infertility Doctor" at their Fargo office.

The infertility doctor told both my husband and I to lose weight and come back in 3 months. That our body mass index (which wasn't very abnormal) was too high and we needed to adjust that first. So we did. The second visit, she was distracted about a trip to Haiti and honestly forgot about us in the exam room for nearly an hour. Needless to say, we asked to switch doctors.

The next doctor offered refer my husband for Urology testing. Just as we suspected (because my husband was an older than average man trying to start a family), he had a low sperm count. They told us we were lucky though because that is not extremely concerning and if the morphology would have been abnormal that would be concerning.

They recommend Intrauterine insemination. Long story short, after we committed to the IUI procedure, we hardly ever saw the doctor again. The department's protocol was to have appointments with the LPN Infertility Coordinator. Every time I came to this clinic, I had to be in the OB waiting area and be surrounded by pregnant women and babies, at this time in my life it was the most horrific thing I had to endure. I would bury my face and cry a lot of the time. We were hurt, angry and broken. Every time I spoke to the LPN I.C., I asked her what the next step of treatment could be, or what the next medication we could try was. Her answer was always "Nothing. This is the route we take and the only route there is." Being I work in healthcare, I know that is NEVER the truth. There is ALWAYS another treatment option of some kind and in some fashion. The LPN I.C. was serious, stern and lifeless. We dreaded attending and leaving every single appointment.

Now, you may be sitting there wondering how could we be so dumb. How did we not know better to switch doctors, or clinics, or to look for further answers. The answer is. We simply didn't know any different. I was extremely embarrassed, ashamed and angry with myself/ my body and I would not allow my husband to share this struggle we were undergoing with anyone else. I certainly was not about to admit to anyone we were failing at starting a family. I held myself accountable and am too hard on myself to achieve success with something to allow anyone to know that I couldn't accomplish something that so many other woman/couples in this world can.

I did not realize this, but I was in a deep, dark depression. I went to work, was miserable at work and made everyone around me miserable as well (I know this now). I went home, and slept on the couch next to molding dishes of cheap, processed foods I ate at some point. I hurt. I

physically hurt and was attending chiropractor and massage appointments much more than normal. But, I thought the cause was my physically demanding job. Those Providers assumed it was. They had no idea it could be depression. My career suffered significantly and was in jeopardy on several occasions. All I remember is that my husband did his best to normalize things and to remind me that life is going to be what's it's going to be. So to just try and enjoy it as it goes. But, that was not physically or mentally possible for me at the time. Lord only knows how he was really doing. How his physical and mental health was. I was in no state to recognize.

After several appointments with the LPN Infertility Coordinator and 4 failed IUI's. I broke. I had a "breakdown" at my parents home on Thanksgiving day 2013. After 3 years, of hiding, avoiding, lying I broke. My body and mind couldn't take one more second and it just starting crying uncontrollably while trying to tell our story. I was convinced I know longer needed to be on this Earth because my body couldn't do what it was created to do- become a mother. My mother and sister sat, listened and cried with my husband and I. Then, my Mother told me my husband to take me to see a doctor who can get me the mental health help I need, and bring me right back to her. So he did. We went home and I saw the first doctor the very next day. I don't think it took her long to realize that I needed medical intervention because I could stop crying in her presence either. She prescribed me an anti-depressant and assured me she chose the one that is safe for "when I become pregnant". I'll never forget that and have since thanked her for those promising words when I was at my most lowest point.

While taking this medication, at one point, I tried to overdose on it. Telling my husband there is no point in me staying on Earth. He deterred the attempt.

Our infertility journey changed a bit because I had told some people about the situation. I soon decided to reach out to a different clinic based on a recommendation from my mother. Who, little did I know, had knowledge of others like me and their stories. She recommended a specific Doctor. This doctor's nurse not only took my phone call, but also recommended I send my our records to that doctor for review before making an appointment knowing that his Infertility care options were limited. The doctor reviewed our records and the nurse called me back with a personal referral. The referral was to Sanford Reproductive Medical Center in Fargo, ND. She informed me the doctor refers to this facility regularly and feels that is where I would best be cared for. How nice! I will never forget the kindness that doctor and nurse provided us! This rarely happens now days unfortunately.

We finally found our home at Sanford Reproductive Medical Center. These doctors and nurses were experts in exactly the battle we were undergoing. The facility was licensed to provide the treatments and medications we needed (MORE TREATMENT OPTIONS, I knew they existed!). I still cannot believe to this day that the LPN I.C. and doctors we saw for 3 years, did not tell us about the existence and licenses this neighboring clinic of theirs holds. A place for us to have hope. To move forward. To regain a little bit of our health that was suffering significantly.

We chose to do 3 more IUI's with different medication choices than we reviewed with the first 4 at the other clinic. Then the doctor looked at us with honesty, confidence, and sympathy in his eyes and recommended to us to move to the next step.

I had been goggling, infertility treatments for years. I knew that In-Vitro Fertilization was a ridiculous amount of money that we would never have. I knew adoption was just the same. I knew my health insurance didn't cover anything once you were labeled "Infertile Female" because that happened to me years ago already and we had been struggling financially as well to pay for any and all of the costs associated with the "infertility tests, treatments and medications" we had had until this point.

Long story short, we took a break. We took a break from trying to conceive. From constantly being told no. From constantly blaming ourselves and each other, from our sex lives that were strained and resentful. From everything a dark, depressing, infertility battle entails. During this break, visited with each other and our families, we did more research, we did more money searching and we created the plan. The last plan.

Fortunately, we ended up being able to chose the best plan for us- the plan I thought was never possible in our lifetime. We committed to In-Vitro Fertilization (IVF). This process is so in depth and very physically invasive that you need many appointments including but not limited to blood work, x-rays, Counseling, medication delivery training and so on. After discussing the Egg Retrieval Process, the Fertilization process and the process of Embryo implantation and long term storage, we signed the legal and medical consents.

We were fortunate enough to complete the IVF process, the Cryopreservation process and the Frozen Embryo process. We have spent at least \$100,000 on our physical and mental health infertility journey and it is still ongoing. When you are in this, you not only need care at the Reproductive Clinic, you may need Physical Therapy, Mental Health and Financial Counseling, nutritional counseling and so on. It is more than one can ever imagine.

Chad and Amber Perdue

Wahpeton, ND

Committee Members,

Waiting, hoping, excitement, uneasy, fear, pain, heartache, anger, wondering, dead inside....these are words that I have used to try and explain to others the rollercoaster of how our journey to bring life into the world started. These are not the words I grew up hearing to describe having a baby or getting pregnant. To the point my 8th grade health teacher told every student we didn't pass his class officially until you had a baby one day. What he and the world fails to teach is that getting pregnant, staying pregnant, and having a healthy pregnancy is Not a given and not Always easy.

Our first ride on this infertility rollercoaster lasted just under five years and has forever changed who I am as a person or has it? I have wondered over the last month after our latest ride took a downward spiral again with heartache, pain, and questions that will never have answers. If in some way my experience in childhood/ young adult prepared me for this ride at least in a small way. The family friends who didn't have a baby and then had two within a few years of each other, my dad's softball teammate and his wife who had a baby and you are told only to touch the baby's feet, babysitting for a family that had one child and a kitchen wall with small figures representing the babies they had lost, and babysitting for a couple who adopted two amazing kids. These are just a few ways infertility impacted my life before I knew my husband and I had a ticket for the rollercoaster infertility had in store for us.

We have received three tickets that have allowed us to see the amazing breathtaking sight of our babies' heartbeats. One of those little heartbeats has run our house for just under five years. Our other two miracles fly above us watching over us each with their own story that leaves us with questions and unknowns. We have also had the heartache of rides that seem to be climbing and then plummet down into the dark abyss.

All of our rollercoasters are not the same and each ride has its own unique track but what I have found is that each of us can shine a light as we pass one another to help us not feel so alone as we put on our brave face and hold on for the ride, hope for that golden ticket.

Bethany Peterson

District 26

It's hard to start my testimony in recent terms, because I feel my story started as a little girl, always wanting to play "house" or "mommy". I was born to be a mom and to have a family. I felt these feelings deep in my bones.

I met my amazing husband in 2010, and the day we began dating I knew we would have a family one day. I had so many hopes, dreams and desires of what this could look like in our future. This future turned out to look so different for us. After being together for over 10 years and trying "naturally" to conceive for 3 years, we sought medical help and support.

Seeking medical help was a scary moment for us because we didn't know how this would help achieve our dreams of having a family. Especially when it came at such a financial cost. We went through multiple interventions with the big black letters on our charts of "unexplained infertility." This diagnosis didn't answer any questions and only added to the expenses, since multiple interventions were unsuccessful.

The feelings of isolation, disappointment, and never-ending financial burden weighed on our marriage. We knew we wanted a family, but were worried now that if we did conceive and have this miracle come into our lives how are we going to provide for this family? We applied for personal loans, maxed out our credit cards, and borrowed from friends and family. This climbing debt was hanging over us, and made us feel guilty for wanting this so bad while living paycheck to paycheck.

Today, we still struggle paying off this debt that has accumulated for us over the years while we were trying to conceive. Our story has a bright spot. We had our beautiful twins in July 2019 through IVF. We should be enjoying this new time as parents, but we continue to stress over meeting our bills even years after our infertility treatments.

The best aid for these couples can come from HB 1147 and expanding insurance benefits. Supporting strong family units, and relieving financial stress on new parents benefits everyone! This suffering doesn't have to hit couples and families both emotionally and financially

Sabrina Olsen – West Fargo ND- District 16

Dear Committee Members,

We are infertility doctors who serve all of North Dakota. We see first hand the issues our patients face when going through infertility treatments without insurance coverage. Infertility is a disease affecting 15% of all Americans between the ages of 18 and 35. As women age, this rate increases dramatically. Infertility tugs at the basic fabric of a marriage and an individual's sense of self worth. People with infertility suffer anxiety and stress equal to that experienced by people with cancer or AIDS. Once a couple decides to pursue infertility treatment, often after years of trying, they are faced with a daunting array of tests and procedures to help them achieve the most basic dream most of us have, to become mothers and fathers. Another side of infertility is the young patients who have been diagnosed with cancer and must undergo fertility treatment to preserve their ability to have a child. Many cancer therapies such as surgery, chemotherapy, and radiation carry the risk of permanent sterility. Imagine being a 22 year old college student and dealing with cancer, IVF, and a dying parent in the very same week. Now imagine that there is no insurance coverage for this basic treatment. It has been shown that fertility preservation is linked to better outcomes with cancer treatment. Cancer patients who undergo fertility preservation are doing something that is based in hope, and an expectation of cure. If their insurance plan is one of the few that cover IVF in North Dakota, imagine how distressing it is to discover that their insurance won't cover fertility preservation because they have not been "trying" long enough? A 14 year old boy with Hodgkin's disease has not been trying to conceive a child for more than 2 years. A 17 year old girl with a rare ovarian cancer can't take 2 years to try to get pregnant before her cancer can finally be removed. Restrictions of this type can harm patients, and result in delays of cancer treatment while they try to maximize their fertility preservation. All of these people really exist, and all of these stories are true, and happened in the last six weeks.

It has been shown that when infertility is covered, patients are more likely to be successful and remain in treatment until they achieve their goal. They are also more likely to abandon futile treatments in favor of more effective ones, ultimately spending less on fertility treatments and conceiving more quickly. Finally, they are more likely to use safe and effective treatments, minimizing the risk of twins, triplets, and more, and have healthier pregnancies. Infertility treatment encourages patients to stop unhealthy behaviors such as smoking, alcohol use, and poor diet, because they know this will help them succeed. Often these positive health changes are continued after they are successful. That reduces overall healthcare costs as well.

North Dakota prides itself on being a family friendly state. We value family time, and want the best for our kids. Good infertility coverage attracts the best and the brightest to our state and encourages them to remain here and raise their children here. Let's live up to our values, and show that we value family by covering infertility in North Dakota.

Thank you for consideration of this important bill.

Christina Broadwell, MD

Steffen Christensen, MD

Sanford Reproductive Health Clinic, Fargo, North Dakota

Dear Committee Members,

Anyone under 35 is recommended to wait an entire year of being unable to conceive before discussing any infertility options. I was 31 years old. My husband and I started our infertility journey in September of 2018. We did our first intrauterine insemination (IUI). It didn't take. We didn't understand why but were optimistic and kept trying on our own for another 6 months. After nothing took, we did another IUI in May of 2019. It worked. I can't even write the words to tell you how happy we were but that feeling was short lived. At 6 weeks pregnant we were told we miscarried. I had no words. People hear the word 'miscarriage' all the time but "it's never going to happen to me". My doctor told me this is more common than people realize but the odds of it happening again were rare. It was only a 20% chance that I would likely have another in the future. As the shock was still wearing off, we miraculously got pregnant on our own for the first time in 2 years of trying. It was August of 2019. We were overjoyed and thought this was our time. Five weeks later, another miscarriage. All I remember from that visit to the doctor was him again reminding me that it was only a 20% chance it would continue to happen and again that it was very unlikely. My emotions took over. I was numb. I had heard that before. I stormed out of his office, got into my car and sobbed. Never ever was there more of a time that I didn't want to beat the odds. We kept trying and again got pregnant on our own in January of 2020. I'm not even sure I was excited at this point. To be honest I was terrified. I had been down this road twice already and never wanted to look back. As our luck went, another miscarriage. The defeat was unbearable. Keep in mind all the meanwhile over the course of the year our miscarriages were taking place, my husband and I were poked, prodded and invaded for all sorts of testing to make sure there was nothing 'wrong' with us. It turns out there was nothing abnormal about either of us, but I personally had never felt more like a failure. Despite our odds we kept going and had 2 more failed IUI's in August and September of 2020.

Throughout our journey, I had asked multiple times about IVF or any other options for infertility, which is what my diagnosis was through all of this plus a second "diagnosis" of reoccurring miscarriage. My doctor told me that with nothing abnormal coming from any testing for me or my husband, IVF was the only other option but that it wouldn't be considered a recommended option until I had multiple miscarriages. Well apparently, 3 is the magic number (along with our 4 failed IUI's). It wasn't good enough to be considered a failure the first time, we needed to suffer twice more before our situation was considered a 'problem'. We were referred for an IVF consultation in October of 2020. At that consult we were told that our insurance covered nothing for infertility so if we were going to pursue IVF, we would need to bring \$17,000 with us to our first appointment or we could not have a first appointment. We were stunned by the initial dollar amount. We knew it was going to cost us, but that much required for an up-front fee was mind-blowing. We talked about the financial options we had, which were few, and decided that the only way to do this on our own was to take out a home equity loan. Luckily, our saving grace came when we looked into an old, grandfathered plan that my husband's job had as an option. It covered a one-time benefit up to \$20,000. We jumped on it. However, we had to wait another 2 months before January 1 would come so we could officially use those insurance benefits. More time lost. I am now 34 years old.

We have our first calendar appointment to start the IVF process next Tuesday. I have so many emotions about it, but I am relieved that it is finally happening. If everything goes perfectly planned and a miracle occurs from this journey, I will be a 35-year-old mother. As you may know, women 35 and older have increased odds of a 20% chance of having a miscarriage. The whole reason my husband and I am on this journey.

As I write this, I realize there are far worse stories and journeys than my husband's and mine. In fact, I could tell you a few. However, all stories matter, and infertility was not a choice for any of us. I can't speak for others but after waiting years to start the journey to having a family, another 2 months for the insurance coverage seemed like a lifetime. I realize we are very fortunate to even have that option as others do not, but it was still more time lost for us. During this entire journey the bill was being paid 100% out of our pocket. No deductible to meet, no co-pay, just an unfortunate answer that the current ACA health insurance plans will not cover any cost for infertility. The process wasn't only hard mentally and physically, it was also financially draining. At this stage of our journey, we have spent roughly \$15,000 out of pocket on IUI's, genetic testing, ultrasounds, seaman analysis, tubal flushing, numerous blood draws, etc. Our one-time benefit is exactly that, one time. As I move in to the 35-year-old statistical age range, coupled with my already reoccurring miscarriage diagnosis, my husband and I have zero guarantees one round of IVF will even work. Then what? We have zero other options than to ask for your support to help us build our family or to take out that home equity loan I discussed earlier. After an almost 4-year journey of failure to have a baby and \$15,000 already gone, I would much rather write this request to you. I have never fully told my story to anyone, not even family. Probably out of shame but I am forced to tell it to you now. People who are strangers to me. People I will more than likely never meet, but I need you. My husband and future family need you. One in six families need you. Please help.

Callie & Ryan Schnell
District 8

Support HB 1147

Dear Committee Members

I am a constituent and am writing to ask for your support of a bill that will help many North Dakotans who struggle with infertility.

Infertility is something that nobody expects. As a girl you grow up planning to have babies and raising a family it is part of your right of passage in becoming a woman. Infertility makes you feel like part of what you get to experience as a woman has been taken away from you. Experiences like being a mother, growing a baby inside of you, the little kick, the little hand pushing out, the not so pleasant pressure on your bladder, have all been taken away from you. You don't get a say in it. It is just the hand you've been dealt and you get to figure out how to cope. Infertility is hard, it makes you question if God doesn't want you to have children, maybe God doesn't want you to have children with your spouse. Maybe you will be a terrible parent and that's why you don't get to have a baby, maybe that baby will die and God knows that's something you can't handle so the alternative is to not give you that precious gift. Going through the process is very hard. Month after month you're disappointed, you have to tell your spouse, "Maybe next month, we'll try again." One of you has to be the positive one, and it isn't easy. You have to take hormones that make you feel terrible & make you feel crazy. You don't even like being around yourself. Many days my husband would ask me "when do I get back the girl I married?" The simple answer is when I can get pregnant or when I can stop taking these hormones. Doctors don't tell you that after you stop taking these hormones your body is messed up. Your cycle is not normal & nothing is like it was before. They don't tell you that by taking these hormones it can actually cause you to have other hormone imbalances that you have to figure out. So not only do you not get to have that precious gift that every little girl dreams of, but you also get to deal with the awful aftermath of it.

Co-works, friends, & family feel sorry for you, but you don't want their sympathy. You don't want to people to feel bad because they have gotten pregnant and you've been trying to for the last x years, they feel bad because they are able to conceive and you're not, they don't want to rub it in your face, so they wait to tell you. You're the last one to find out. You want to be happy for them, you are happy for them, but at the same time it is hard to see your friend's dreams of becoming a mother/father come true when you want the same thing so badly. You would never wish infertility on anybody, but you sure didn't expect it for yourself either. Friends don't want to hang out with you because your whole life is consumed with trying to have a baby, you're crabby, and not fun to be around. They don't understand that you don't really want to be around anyone or what you're going through. Nobody can understand except others that have gone through this experience.

My husband and I are fortunate to have good jobs, good insurance, and are financially stable. In our case insurance covers a lump sum amount for infertility. However, insurance doesn't cover the time off of work and travel expenses to make it to weekly doctor appointments. When living in a rural area the closest specialist is 75+ miles away. We met with multiple specialists, one Doctor categorizes you in the Poly Cystic Ovary Syndrome, and the next one attributes our problem to my husband chewing tobacco. So we don't actually get any solid answers on why we are unable to get pregnant, just basically that we need to move forward and take other measures to try to conceive. After unsuccessful IUI's we tried natural phatic acupuncture that is not covered by insurance. By the time we got to the IVF treatments we only had a small amount left because when you start going to the doctor for "infertility" it is then categorized under that and the lump sum amount starts to dwindle quickly. We had to decide what and how to spend the remainder of what we had left. We paid for the hormone shots out of pocket so that we would

get a discount on them and the remainder of the funds could be used for our IVF. We had a lot of success off the bat, things were looking good we had 6 good embryos! About 5 days later we get a call that nobody expects "I'm sorry all 6 of your embryos stopped developing so we will need to try something different." We weren't told that it was even a possibility that our embryos could stop developing. Logically, of course that is something that can happen, but it isn't something that you expect, or that was even on our radar of possible failure. When we asked why our embryos stopped developing they couldn't give us an answer, so what did we exactly pay for? Not only do we not get a baby but they couldn't give us a reason. I mean, you expect to at least have them implanted and then possibly not take, that we were prepared for. But none the less we can keep trying and in essence start paying all over again and have the possibility of the same result, that we've spent the last 6 years getting, Thanks but No Thanks. Since our IVF failed we gave up the idea of having our own biological children and it broke our hearts. I cried a lot and my husband felt like he didn't know how to help me, this was one problem that he couldn't fix. We prayed, we talked to family, and we decided to move on to other alternatives, adoption. Adoption is also very expensive and added to the financial strain which in addition adds strain to our marriage.

Sincerely,

Lindsey Schutt
District 33

December 30, 2020

To the Honorable Representatives of North Dakota,

My name is Ariel Schwarzrock, and I am a constituent of the 41st district. I wear many hats as I am a bachelor's prepared registered nurse, clinical instructor for undergraduate nursing students, a graduate student pursuing a doctorate of nursing practice, and a small business owner making candy.

I am writing to all representatives as a voice for those in your districts struggling with infertility. Infertility is a whisper in the background of so many lives, but frequently unspoken. Let me be a voice for all of those who long to be heard but are afraid to speak. While there are many reasons a person may be infertile, the journey and treatments bring about similar stressors and barriers to treatments. Treatments and medications for other conditions are covered with insurance, but ones for infertility are still being debated.

Insurance coverage, medication availability, and needing support are all areas my husband and I have struggled with as we venture on our journey of infertility with professional assistance. I cannot fathom how these same barriers keep arising and are allowed to be repeat offenders to those wishing to grow their family.

While we are blessed to have medical insurance, I am continually surprised what is and is not covered with our insurance. For labs and ultrasounds, we need to meet a deductible specific to infertility before insurance will even help with payments. Half of the medications we need are not covered at all with our insurance. And of the ones that are covered, sometimes the out-of-pocket cost is cheaper than the copay.

When ordering fertility medications, our insurance prefers us to use a mail pharmacy. Treatments for infertility are very time sensitive. Having to mail order medications is not convenient and leads to extra stress when going through treatments. Timelines are made as the treatment progresses, so the chance of not having medications on time is a real fear with mail.

Finally, we decided to reach out and find a local support group. Becoming vulnerable and sharing is a scary thought. We searched for a local support group for couples in our situation. Surprisingly, resources are scarce. We are hopeful for a virtual group that meets monthly; our first meeting will be towards the end of next month.

I hope you find these barriers to be unacceptable and work with our community and state to spark change. Why shouldn't infertility treatments be more accessible and better covered? In the same way a diabetic does not choose to need insulin, infertile individuals do not choose to need treatments for conception. Below I have included a glimpse into our story. Please feel free to reach out with any questions you may have.

Thank you for your time and support; your representation is appreciated.

Ariel Schwarzrock, RN, BSN

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A Glimpse into Infertility

My husband and I have been married for nearly four years. It was towards the end of our first year of marriage we decided to open the possibility for starting our family. We knew we wanted to have a family and recognized timing was not a luxury we would have as a choice. When we first were married, we thought we would take the first year or two settling into our lives together and then add in children. Now we wonder why we wasted time preventing pregnancy for a few months as now it has been over three years of trying for a family with no success.

I have polycystic ovarian syndrome (PCOS). PCOS causes hormone imbalances leading to my body holding on to eggs and forming cysts rather than releasing an egg each monthly cycle. This also means monthly cycles turn into two-to-three-month cycles with no knowing of when or if an egg is even being released. Other unwanted symptoms include increased acne, extra body weight, and excessive hair growth in male patterns.

This year my husband and I started to seek professional assistance with our family. We just started our first round of treatments in December 2020 and ran into countless roadblocks. What I do not understand is how there could be so much stress and so many roadblocks if there are others dealing with the same difficulties. I have heard the whispers in the background of the same exact problems that we ran into and cannot fathom how these troubles keep arising rather than being resolved.

When we were ready to start our first treatment, we contacted the clinic to start the process. My plan included taking a medication for several days at the beginning of my cycle. Ultrasounds are frequent occurrences during treatment to ensure everything is progressing as planned and help determine when to take the next steps including additional medications.

One of the difficulties we ran into was obtaining medications. Our insurance works with a mail pharmacy for fertility medications. However, not all medications are covered and one of the medications was actually cheaper to pay out of pocket than the copay. Of the three medications we were ordering at that time, we only used our insurance for one.

Not only figuring out the bill for our medications was a difficulty, but by having our hands tied to using this specific pharmacy we were unsure the medications would arrive on time. Fertility treatments are extremely specific and timed. For our timeline, we would be needing the medications over Christmas weekend. We knew with the holiday coming and the increased mail over the holiday season we should start the process of obtaining medications early. After countless hours on the phone and coordination we had it all set up for the medications to be delivered the Tuesday before Christmas. Twice our order failed to deliver. What happened? Did the pharmacy not send them out? Did they get lost in the mail? We will never know.

With Christmas Eve on Thursday and decreased business hours we were rushing to find solutions on Wednesday. The pharmacy we ordered from said they found a local place for us to pick up the medications. These partial orders would tide us over until our third package arrived the Saturday after Christmas. Local, to the out of state pharmacy, meant they found a physical pharmacy within eastern North Dakota. They wanted to send us to Grand Forks. We live in Fargo. We found this out at the end of the afternoon on Wednesday. A winter storm had been blowing all day, and while visibility was better by the evening, the winds were just as terrible. We were expected to go on a 160-mile trip in high winds, icy roads, and dark skies just to pick up a few medications because packages continually failed to deliver.

My husband did some research and found that the pharmacy in Grand Forks had a location in Fargo. He had called and talked to this Fargo pharmacy earlier in the week due to our

first packages failing to deliver and trying to find alternatives should we need them before closures for the holiday. The Fargo pharmacy is actually our normal pharmacy we use for other medications. Luckily, the branch in Fargo did have our medications in stock and we were able to go pick them up. What I do not understand though, is why a pharmacy we are already established with could not be approved as the primary pharmacy to obtain our fertility medication from. Why do we need to mail order them in and deal with an extra layer of stress during an exceptionally stressful time?

Thursday morning came. The next step was an ultrasound. We hoped for a dominant follicle to show on the pictures so that we could progress to the next steps over the weekend. Sadly, we found my body produced a cyst instead. Defeat is the only word to describe how we felt. We worked so hard to do the right things, find medications, and for what? To be put on hold again. I cannot help but wonder if all the extra stress obtaining medications during the start of treatment lead my body to forming a cyst rather than progressing into a dominant follicle. Stress does play a role in PCOS and leads to worsening hormone imbalances creating worsening cyst formation.

My husband and I had talked previously about finding a support group as we started this journey. However, admitting the struggle and being vulnerable drove us to postpone for a long time. After the events with obtaining medications and the disappointment of our first treatment we decided it was time to put our anxieties aside and find a community who understands.

To our dismay, searching for a group online was difficult. We wanted to connect with others in our area but could not easily find any local groups. Granted, with a pandemic occurring, we knew we would not likely find in-person meetings but hoped for a virtual venue. We sent a few emails to groups appearing to be in North Dakota. I even wrote to my provider asking for

local support groups and resources. Of all the messages I sent I was confident my provider would have some answers, but even she responded she would have to do some research and did not know of any. We only had one email response, and we are hopeful to connect with others through this organization.

With the search for support groups, I was also disappointed to find descriptions mainly focusing on women. Women are not the only ones who deal with infertility. Men also can have barriers. No matter which side the barriers are on, the spouse needs just as much support. In our case, we would love to attend a support group as a couple. I joined a Facebook support group and was excited to connect with others in this way. I started scrolling the posts and found that many are in my position. I long for a community and support, but I do not know what to say. The posts were few; it seems we are all waiting for someone else to break the ice.

Today I write in hopes of breaking the silent suffering. If I did not struggle with infertility from PCOS I would have a toddler playing in the room and a baby in my arms. Instead, I have tears in my eyes and a longing heart. This coming spring, I will graduate with my doctorate. A few years ago, I thought I would feel fulfilled to obtain this degree before I turned 30 years old; I had a sense of accomplishment. However, now my desire before my 30th birthday next fall is to have a child in my arms. I fell into the illusion of having the choice of when I wanted to grow my family during my 20s. I have dreams of a big, loud, happy family, but as I near my 30s I wonder if we will even be able to have one child before my childbearing years pass by. Our journey is far from being over. I hope our story inspires you to help make the change for all those suffering in silence. Let them feel seen; let them feel human.

Dear Committee Members,

My name is Kelsey Knodel and I am a military spouse to a North Dakota Active Guard Reserve Soldier under Title 32. Five years ago, my husband was freshly home from a deployment in support of Operation Enduring Freedom, when we began discussing the hopes to grow our family. After one year of trying, we realized we were the 1 in 8 couples struggling with infertility. We spoke with our medical professionals and a referral was made for reproductive medicine. We waited to be seen and had many tests, time off work, early morning or lunch hour appointments, pokes, prodding, all to get to a diagnosis of unexplained infertility. The grief you feel receiving a diagnosis that can't be explained was unbearable. We tried to hold onto the hope that our dream to have a child would be fulfilled someday. Shortly after meeting with our medical team, they discussed the next steps for assisting us in our goal to grow our family. During this time, we were able to meet with a financial representative from the reproductive clinic. To hear that TRICARE covers diagnostic testing for analysis was reassuring; however, to hear that they do not cover any of the procedures including intrauterine insemination (IUI) and invitro fertilization (IVF) was disheartening. The financial counselor quoted us around \$3,500 for an IUI procedure and close to \$25,000 - \$35,000 for IVF depending on medications prescribed, genetic testing results, and if a fresh or frozen transfer would be recommended. Research states women have a 20% chance to obtain pregnancy each month, for women diagnosed with infertility that number drastically decreases to around 0-11%. In our experience, the specialist recommended starting with least invasive procedures first before moving to IUI or IVF. As we progressed through months of treatment and recurring negative pregnancy tests, the conversation led to IUI and IVF. Knowing TRICARE does not cover such procedures, required us to make the decision that would impact us financially. Living a military lifestyle requires sacrifice, for your family, community, and country. The thought of sacrificing our dream to grow our family based on lack of insurance coverage was discouraging. Less than one percent of our nation serves in the military. Of this almost one percent, many military families experience the devastating diagnosis of infertility. The sacrifice of a soldier's selfless service and their spouses' support and dedication to their nation should afford the additional rights towards progressive insurance coverages related to infertility. Selfless service, courage, honor, duty, are all values of military families. So today, I ask for you to have the courage to stand in support of military families, leading the way to complete and accessible infertility insurance coverage.

Kelsey Knodel – Military Wife and Infertility Patient

Dear Committee Members,

This is my life with infertility. As a young child all I ever wanted to do in life is be a mom so when I found the love of my life I knew that someday that dream would come true or so I thought. After our wedding we started trying for kids right away and soon it had been a year and still nothing was happening. So we meet with an obgyn in Grand Forks ND and after some tests we found that I don't ovulate enough to conceive and my husband has a low sperm count two factors that make it crazy hard to have a baby! So I was put on clomid for six months. On the 6th month we got great news a positive pregnancy test!!! After we had the baby I had a blood clot and was in the ICU for treatment of that and sent home on blood thinners for 6 months after that 6 months we started trying again on our own but nothing. So we in listed the help of our OBGYN and again I was put on Clomid for 6 month intervals and nothing worked. I did 12 months of that and nothing. So we moved forward with an IUI in grand forks and that didn't work. We were then referred to Fargo's infertility clinic and from there we tried Femara and the trigger shot along with IUIs and ultrasounds and still nothing. Besides the discouragement of not being able to have another child we were now faced with the medical bills that came with it because my insurance does not cover anything after that diagnoses of infertility is made. Which being me to the other side of this diagnoses why are insurance company's so quick to help you get your tubes tied or a vasectomy but not to help couples have the families that they have always wanted? For my husband and I we would love to open our hearts to and other child weather it's our own or ours through adoption but with that being said the out of pocket price for IVF and IUIs even Adoption are so crazy priced and are not a reality for us when insurance doesn't help at all.

Kellee Thacker (mailing address)

Po box 415

Cavalier ND 58220

Dear Committee Members,

INFERTILITY: It's a word that I have seen, heard, and dealt with repeatedly. I've seen it always under the list of "what's not covered" on my insurance benefits. Heard it from my doctors, and dealt with since 2013. When you grow up you're taught about sex, and the biggest take away from that class is HAVE SEX and you WILL get PREGNANT! Then there is the classic, first comes love than comes marriage, then comes the baby in the baby carriage. Boy, that could not be any more wrong for my husband and I. Since an early age I knew I always wanted to have kids; however for some reason that was not in the cards for us. It began in early 2013-2014 when I met with my doctor who referred me to a reproductive specialist. We were put through a series of tests. Lab draws, semen samples, numerous ultrasounds, HSG. Of course you instantly become stressed because you think, what is wrong with me? Then on top of that stress and worry, you find out that NONE of those things are covered because your insurance doesn't have infertility! Not even a normal ultrasound that I would get if I actually WAS pregnant. How does that make any sense? If I am pregnant and get an ultrasound I pay \$0.00, but if I am being monitored for infertility each ultrasound cost me \$254.00! We started out small by trying different pills, luckily these were affordable through my local CVS (not covered by insurance) (I took Letrozole and Clomid) Each time it was have labs drawn, have an ultrasound, take a pill for 5 days and repeat. Our next step was to try the injections. It was the same concept of the pills, except it involved ultrasounds approximately every THREE days! And these injections were outlandishly expensive. Let me break it down for you. When doing the shots you are needing about 5-6 medications, depending on your "reason" for infertility.(Menopur, Gonal F, Ganirelex acetate, novarel) Each cycle I spent at least \$5000 just for the medications, all out of pocket. Now after I did one round of the injections, it was finally time for me to do an IUI (intrauterine insemination). My husband drops off the sample and we do the procedure right there at the clinic. (There goes another ~\$1000.00. We patiently, anxiously await 14 days before taking a pregnancy test. I was so nervous and scared that I didn't even want to take a test at home because I was afraid to see the stark white line that I had always seen. I went into the clinic for a lab draw and low and behold I was pregnant!!! Unfortunately shortly after I started to have some bleeding and it was determined that I had an ectopic pregnancy. Thank God it was found early as those can be very serious, resulting in a lose of a fallopian tube or even your life!!! I was DEVASTATED! I finally got pregnant and now I lost the baby. And now I get to fork over ANOTHER \$5000 +. The next round we did the injections again; however I know produced "too many" eggs that they did not want to do IUI as that could result in a multiple pregnancy. So now we are about \$10,000+ into this process and our credit card bills are pilling up! When meeting with our specialist it was recommended that we move onto IVF. (in vitro fertilization) We did yet another round of injections, labs, ultrasounds, and a drive to Minnesota. THANKFULLY we were blessed with a healthy baby girl in December of 2016. We would love to have one more (since I have 2 eggs frozen yet) but I can not imagine spending even more money again. We have put a lot of our costs on credit cards, used medical flex, and have had help from our family. Please consider changing the law for mandated infertility coverage. Not only does this create a huge financial strain but also it puts a strain on our relationship with your spouse. I read something online tonight as I was researching and it

is so true. It read something like “Its like having a lump found in a mammogram and that is covered by insurance, however not having insurance to treat the breast cancer” So insurance is currently saying ok yep we covered your diagnostic tests to determine you have a form of infertility, but now your on your own to figure out how to “fix” it. I don’t know if it’s because I am open about my struggles or I’m more aware or its becoming an increasing problem, but I know SO many women who have been on the same struggle as myself and husband. Please help these families feel whole and allow them to have their dreams come true!!!

Heather Vettle
Bismarck
District 7

Cory and I met in April 2013. For him it was love at first sight but for me I had to get to know more about him. He popped the big question on July 4th 2014 and even though his proposal didn't go as planned I still said yes. We got married June 11, 2016. Cory has four older siblings (two brothers and two sisters) and just about all of them are married and have kids so we wanted to start our family soon after we got married.

After trying for a few months, we were so blessed to be pregnant, not believing it could be true we wanted to tell everyone but kept it somewhat of a secret. Then in January 2017 our lives would change forever. I had my first miscarriage and was completely devastated. After losing our baby I was so depressed I would just put on a happy face to everyone else. I was so upset as to why I lost my baby but we decided to keep trying. A few months later the same thing happened I wasn't as far along but still it was a struggle. I also started to have terrible side pain and never felt very well. This is when we decided to start going to a fertility specialist. The doctor told me all I had to do was lose weight and I'd be fine, there was no other help beyond that. We took some time off of going to doctors for help because at this point, I was so depressed from the lack of help it was getting way too emotional.

Cory and I kept trying to start our family and decided in the summer of 2018 that maybe adoption was the only way to have our family. I found an online support group with women that have infertility problems and it helped me a little to know that there are so many other women out there that have the same problem as me, a problem so many people refuse to talk about. Cory convinced me to go to a new doctor at a different hospital for a second opinion. After a talk with her we were told she didn't see any reason why we wouldn't be able to have our own baby-I was so excited. A few months later still no luck I had a HSG test done to see if my tubes were open, one of my tubes was blocked so they went ahead and unblocked it. After a HSG test many women have lucky getting pregnant but as for Cory and I still no luck.

At this point my doctor started talking how I might have endometriosis. I started researching it and I had so many of the other the symptoms I was terrified that this might be the reason I can't have kids and would have to live with this awful pain on top of never having a baby very easily. At this point it has been two years since we started trying and I wanted answers. I decided to have a laparoscopic surgery to see if I had endometriosis. The test result came back and I thankfully did not have endometriosis but had a golf ball size cyst on my ovary which was causing the pain.

Once I recovered from surgery, I had such a high feeling it would be our time to finally have our family-but still no such luck. I started looking into other ways for Cory and I to have our own kids. However, after endless research I found out that other options like IUI, IVF and so on would cost hundreds each session or even thousands. The thing about other options to conceive is that insurance doesn't typically cover them so it is an all out of pocket cost. We're talking around \$4000 each round to try to have a baby and if that round fails- which it usually takes a few rounds of help to finally get pregnant the amount of money is more than either Cory or I have and without the help of insurance we couldn't afford to spend the money and potentially not get a baby. At this point, Cory and I have spent thousands on just trying to pinpoint the problem. We now were just praying for a miracle because there is no way that we could afford any other options. We came to the point of looking into adoption as we didn't think us having biological children was an option.

Fast forward to August 2019 we found out that our prayers had been answered and we were expecting a baby! From the very start this pregnancy has been very terrifying from almost losing him early on to being diagnosed with complete placenta previa at 18 weeks. Although Cory and I have had many ups and downs trying to have a family we couldn't be more excited to have our little miracle. He is such a joy in our lives and having that kind of happiness shouldn't be stopped because there is no help from insurance.

Jamel and Cory Wald- District 28

Infertility Testimony

My husband and I started trying for a baby shortly after we were married. We wanted a big family so we started right away. After a year of trying with no luck we started to doctor with our OB in Fargo. After tracking cycles, tests, appointments, lab work I was diagnosed with PCOS. We began oral fertility medications which resulted in needing ultrasounds every 2 days to track follicle growth. After no success we moved to another fertility medication which also needed ultrasounds, blood work, labs, testing. No results there either.

Our regular OB doctor suggested we meet with a fertility specialists that came from Minneapolis to discuss further what to do. This was our only option because my insurance selection was Essentia health who did not have a fertility doctor of their own so they used Dr. Corfman from Midwest Center for Reproductive Health.

We met with him and he determine “unexplained fertility”. We would need further testing, labs, to determine what the next steps would be. Each time we met with him in Fargo in would be a cost of \$2,000. He wanted to track cycles and try some oral meds until his care to determine the next route which also costed a lot of money out of pocket. After months of tracking it was determined that I would need IVF because of my bodies inability to ovulate.

I would need to do IVF down in Minneapolis which was completely out of pocket (a total of \$20,000). We would also need to put two embryos in because of the financial cost although it was a BIG risk due to my petite frame.

IVF is only done 5 times per year so we needed to wait until the next round to get started. In January 2012 we did our first round in Minneapolis. Again cost of hotel, gas, lodging on top of the \$20,000 it took for IVF. We transferred two with neither taking so it resulted in no pregnancy and out \$20,000.

We met again to discuss next steps which also costed just to have the consult. We decided to freeze our remaining eggs and try again and the beginning of summer because I didn't have enough days to miss from work so we needed to wait until school (I am a teacher) to be done so I could try again. It costed to freeze our eggs with no guar tee they were going to thaw correctly.

In June 2012 we did a Frozen Embryo Transfer. We had 3 eggs to thaw and one didn't make the thaw. We transferred two again which was another risk but due to cost it was our only option. One of the embryo's took at we became pregnant with our son.

Blue Cross Blue Shield of North Dakota has a lifetime maximum of \$20,000 which was easily met. We were able to have access to that using medications and testing in Fargo but they covered NOTHING once I was labeled with infertility. With one round of infertility and IVF wet met our maximum which put us in a position to not be able to expand our family anymore through IVF.

IVF is extremely hard emotionally, financially, and tears a marriage down. We went to counseling (which also wasn't covered) to deal with the emotional stress of everything that comes with IVF. My hope is that other women, including my daughter if this is what she needs will have infertility coverage so she doesn't have to experience the financial burden we did.

Child Number 1

May 2010: Meet with OB doctor due to no period

- Diagnosis: PCOS

May 2010-July 2010: Start Oral Fertility Medication

- (Letrozole \$ 800 per cycle)- no results
- **Ultrasounds (\$300 each)- every 2 days to track follicle growth. A Total of 8 ultrasounds needed (\$2,400)**

August 2010: Financial and Emotional Break

- Meet with OB doctor again
- Going to try new oral fertility medication

September and October 2010: Start Oral Fertility Medication

- Clomid \$1200 per cycle(Not covered by insurance)
- **Ultrasounds (\$300 each)- every 2 days to track follicle growth. A Total of 8 ultrasounds needed (\$2,400)**

November 2010: Meet with infertility specialist from Minneapolis because Essentia Health of Fargo, North Dakota doesn't have their own fertility doctors. Met with Dr. Corfman from Midwest Reproductive Health (\$2,000- each meeting with Dr. Corfman costed \$2,000 of out of pocket).

- Diagnosis: He doesn't think I have the "normal" PCOS symptoms so diagnosis me with "unexplained fertility"

December 2010-January 2011: Financial and Emotional Break

February 2011: Meet with Dr. Corfman to discuss IVF (not covered by insurance-\$2,000)

March-April 2011: Start IVF Testing (HCG testing, lab testing, urine samples)- none covered by insurance \$8,000

- Everything comes back normal

May-October 2011: Continue to try on our own. Saving money and waiting for the January 2012 IVF cycle.

- No results from trying on our own
- **Marriage counseling (\$900).** Lots of financial and emotional stress

November-December 2011: Emotional break

January 2012: IVF #1 done in Minneapolis due to Essentia having no fertility clinics. BCBS of North Dakota doesn't cover out of state doctoring or ANY IVF procedures (\$16,000 for IVF: \$4,000 for IVF meds)

- 21 eggs retrieved, 9 fertilized
- Transferred 2, froze 3 (it costed money each month to have your frozen eggs stored in their facility- \$1500 per month (5 months).
- Cost of hotel, gas, food for 4 days (\$1,500)

February 2012: IVF #1- didn't work

March 2012: Meet with Infertility doctor (Dr. Corfman) to go over results and next steps (**Again no coverage**) \$2,000

April-May 2012: Emotional break

June 2012: Frozen Embryo Transfer #1 (\$5,000): Thawed all three, one didn't make the thaw so transferred the last remaining two.

June 2012: Pregnant

July 2012: Only one egg took so pregnant with one embryo

Child Number 2

March-September 2014: Tracking ovulation for next child. Trying on our own

- No ovulation/No pregnancy

November 2014: Meet with Dr. Corfman to discuss plan for next child. Decide on more testing to see if we could try IUI because we have no frozen eggs left (\$2,000)

- Each meeting with Dr. Corfman costed \$2,000 out of pocket

December 2014: More testing, labs, etc. Numbers look good for IUI

January 2015: IUI at Essentia Health in Fargo. (no coverage because of IUI-\$3,500)

February 2015: Pregnant resulted from IUI

Kelly and Nick Weisbeck

Fargo ND District 45