

## Testimony in Support of Senate Bill 114 for the Senate Committee on Agriculture, Revenue and Financial Institutions

Good Afternoon,

Mr. Chairman and members of the committee, thank you so much for scheduling this hearing. My name is Kim Whitmore. As a citizen of Sun Prairie, a registered nurse, and a bereaved mother, I urge you to support Senate Bill 114 and create a refundable individual income tax credit for the parent of a stillborn baby.



This is a picture of my beautiful daughter, Alana Rose. Her due date was April 15<sup>th</sup>, 2019. Tax day. A day that many American's dread because it means having to scramble to organize all their financial information and hope their accountant finds ways to reduce the amount of taxes they owe. But for my husband and I, April 15<sup>th</sup> was a day we were anticipating with great joy and excitement. We were busy getting everything ready for the arrival of our baby girl. We purchased the car seat and stroller, we took the maternity pictures, we had the baby shower, we moved into a bigger house with an extra room that we planned to transform into a purple butterfly-filled nursery, and we even broke down and bought the mini-van!

However, instead of being born on April 15<sup>th</sup>, as planned, our daughter, Alana, was stillborn on February 26<sup>th</sup> at 32 weeks gestation as a result of an acute total placental abruption that disconnected my baby completely from life sustaining blood flow. The massive internal injury that this caused inside me triggered a rare, life-threatening condition called Disseminated Intravascular Coagulation (DIC). I lost close to 5 liters of blood (nearly my total blood volume). They transfused more than 15 units of blood products in order to sustain my life. I am truly

lucky to be alive today, though for many months I had wished I had died with my baby girl so she wouldn't be alone in Heaven.

Over the next few weeks after Alana's death, I focused on my physical recovery and planning arrangements for our baby's celebration of life. Instead of going to the pediatrician's office for well child checks, I was going to the maternal fetal medicine clinic for ongoing care to monitor my own medical condition. Instead of sending happy baby announcements to friends and family, I was receiving sympathy cards. Instead of singing my baby to sleep with lullabies, I was crying myself to sleep from the grief of losing my daughter. Instead of laying my baby in her crib at night, I was preparing to lay her in a coffin for eternity.

As if losing my baby girl and nearly dying myself was not enough, the story does not end here. A few weeks later, I finally had a call with the human resources manager to discuss my leave benefits. I was shocked to learn that the only benefit available to me was the use of my sick leave, of which I only had a total of 3 ½ weeks accrued after being employed by UW-Madison for the past year and a half. I asked if I received any bereavement days and was told that I could take bereavement days, but I had to use my sick leave to pay for them. I asked about short-term disability benefits and was told that the policy had a 180-day waiting period, meaning I would have to be off work for at least 6 months without pay before it would kick in and pay me 75% of my salary. I could not believe that the UW System, the largest employer in the State of Wisconsin, did not have better policies to support families.

We had just purchased two new vehicles and moved into a bigger house (both with bigger monthly payments) to make room for our growing family. With all the medical care my baby and I received, I ended up paying more than \$5000 out-of-pocket and that is with the excellent State employee insurance. I was also faced with over \$500 in expenses related to planning a funeral and burying my daughter. With all these additional expenses, I could not afford to take a significant amount of time off without pay. So, I started working part-time just 3 weeks after losing my daughter and nearly dying myself. Under normal conditions, doctors recommend at least 8 weeks to recover from a C-section. My situation was far from "normal" and yet here I was, forced to return to work after only 3 weeks while still in extreme pain, both physically and emotionally. Today, I am still dealing with ongoing physical and mental health issues, which require me to, occasionally, take unpaid time off work to cover medical and therapy appointments and days when my grief is so overwhelming it incapacitates me. To-date, I have lost over \$15,000 in income from unpaid leave and lost work time.

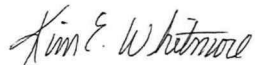
A tax credit on April 15<sup>th</sup>, the day I should be celebrating Alana's 1<sup>st</sup> birthday and taking pictures of my daughter smashing cake into her face, would be a nice "gift" to our family to help ease some of the financial burden and acknowledge that her life mattered. It may even help us replace the temporary grave marker that currently rests at the head of Alana's gravesite because we have not been able to afford to purchase a permanent one.

Unfortunately, my story is not uncommon in Wisconsin. There were a total of 291 stillbirths in Wisconsin in 2017 (according to the most recently published data from the Wisconsin Department of Health). In Dane County alone, there were a total of 73 stillbirths from 2015-

2017 and the rate among Black infants was at least twice as high as White infants (according to the 2019 Dane County Maternal and Child Health Data Book).

I know that my family will survive this horrible experience because of the tremendous support we have from friends and family. However, there are many families with far less financial resources and support who could desperately use the help this tax credit could provide. Therefore, on behalf of Wisconsin families who experience the tragic death of their babies prior to birth, I urge your support for Senate Bill 114.

Thank you,



Kim E. Whitmore, PhD, RN, CPN

**Contact Information:**

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## WISCONSIN CATHOLIC CONFERENCE

TO: Senator Howard Marklein, Chair  
Members, Senate Committee on Agriculture, Revenue and Financial Institutions

FROM: Barbara Sella, Associate Director, Wisconsin Catholic Conference

DATE: December 18, 2019

RE: Support for Senate Bill 114, Stillbirth Tax Credit

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The Wisconsin Catholic Conference (WCC) greatly appreciates the opportunity to offer testimony today on behalf of the Roman Catholic bishops of Wisconsin in support of Senate Bill 114, which creates a refundable individual income tax credit of \$2,000 that may be claimed by the parents of a stillborn child.

Every October, we recognize Pregnancy and Infant Loss Awareness Month, but much of society does not know how to react or help those who have faced the loss of a baby. When a family loses a child to stillbirth, it is a devastating experience that is often coupled with confusion and isolation. A parent's perspective quickly turns from joy to instant sorrow. The process is made more painful by having to inform friends and family of the death of a child and dealing with the reality of mounting health and funeral expenses.

When a family experiences a stillbirth, as one mother wrote "There are often no memorials, no flowers, or notes of condolence..." There is no aid and little acknowledgement. In creating a stillborn tax credit, Senate Bill 114 provides a formal acknowledgement to grieving families that the State of Wisconsin recognizes the loss they have suffered with the death of their child. This acknowledgement comes through a compassionate offer of assistance, a means to help families cope with the mounting challenges they face with such loss.

However, given that many families experience the loss of a child earlier during pregnancy, we would request that Senate Bill 114 be amended to include the unintentional loss of a child prior to the 20-week or 350 grams weight standard that triggers a fetal death report under current law. With the loss of a child earlier in the pregnancy the experience of the family is the same – the same love, the same grief, and frequently many of the same health and related costs. Therefore, these families should be provided with access to the same resources.

As Pope Francis once said, "Every child born is the promise of a life which once again reveals itself to be stronger than death." (*General Audience*, September 20, 2017) With a stillborn child, the love already experienced between parent and child must be acknowledged by our society and our communities must offer consolation for that hidden life lost. Senate Bill 114 is one important way to memorialize this life and provide comfort to those in sorrow.

We urge your support for Senate Bill 114. Thank you.



# JOAN BALLWEG

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CO-CHAIR, JOINT COMMITTEE FOR REVIEW OF ADMINISTRATIVE RULES

41<sup>st</sup> ASSEMBLY DISTRICT

**Senate Bill 114: Creating a Stillbirth Tax Credit  
Testimony of State Representative Joan Ballweg  
Senate Committee on Agriculture, Revenue and Financial Institutions  
December 18, 2019**

Thank you, Chair Marklein, and members of the Committee on Agriculture, Revenue and Financial Institutions for holding this public hearing on Senate Bill 114.

SB 114 creates a \$2,000 refundable tax credit for the parents of a stillbirth. The proposal defines stillbirth as a birth that occurs in this state that results in a stillbirth for which a fetal death report is required. Sadly, in Wisconsin, there are an average of 348 fetal deaths per year. Not only is this a difficult time for parents coping with the loss of their child, but parents of stillborn children undergo many, if not all, the same expenses that parents of a healthy newborn child undergo, such as medical costs and lost wages from missing time at work.

Yet, our tax code creates inequalities between families by not giving aid to parents simply because their child did not take his or her first breath. For example, there are numerous tax benefits related to children and/or pregnancy if the child survived, like the child tax credit, child and dependent care tax credit, personal exemptions, dependent deductions, and itemized deductions of medical expenses. I believe the tax credit created by SB 114 will treat parents more fairly. By helping to recover some of the expenses, it will grant at least some financial relief to those struggling with the loss of a child. Also, it provides an acknowledgement from the state that these children deserve to be recognized. There are at least five other states, including Minnesota and New Jersey, that we modeled parts of this bill after, that grant a one-time tax credit for stillborn children.

Thank you for your consideration of Senate Bill 114.



**Alberta Darling**  
**Wisconsin State Senator**  
Co-Chair, Joint Committee on Finance

Senate Committee on Agriculture, Revenue, and Financial Institutions  
Senate Bill 114  
December 18, 2019

Thank you Chair Marklein and committee members for holding a public hearing on Senate Bill 114. The legislation before you today creates a refundable tax credit for parents of a stillborn child.

Under current law, parents receive a \$1,000 federal tax credit for eligible children. This money is of particular use for new parents, as the credit can aid with the high cost of child birth. However, in Wisconsin, if a child is stillborn, parents are not eligible for this tax credit. By comparison, parents of a child who dies shortly after birth are eligible for this deduction, along with maternity leave.

Senate Bill 114 addresses this inequity by creating a tax credit for parents of stillborn children. A stillbirth is a birth that occurs in Wisconsin for which a fetal death report is required, meaning a miscarriage after at least 20 weeks. In addition to the trauma of a miscarriage, parents of a stillbirth undergo many, if not all, of the same medical costs that parents of a healthy newborn child undergo. Yet, our tax code does not currently recognize these bereaved parents simply because their child did not take his or her first breath.

Senate Bill 114 creates a \$2,000 refundable tax credit for the parents of a stillborn child in Wisconsin. The stillborn tax credit is more than the federal tax credit because even though parents miss work when they have a stillbirth, they may not be eligible for maternity leave. As such, the increased funds are meant to help absorb the costs of lost wages for the time missed during the miscarriage and recovery.

I'd like to thank the many brave parents of stillborn children who reached out with their support of this bill. I would also like to thank Representative Ballweg for her leadership on this issue. In passing Senate Bill 114, Wisconsin can join other states like Minnesota, Indiana, and Michigan in aiding parents of stillborn children. I hope I can count on your support for Senate Bill 114.

Mark Pepoy  
720 Clede St  
Oregon, WI 53575

Senate Agriculture, Revenue and Financial Institutions Committee  
Hearing: Dec 18 @ 1:01 pm in 201 Southeast  
Senate Bill 114

**Relating to:** creating a refundable individual income tax credit for the parent of a stillbirth.

Sponsored by Senators Darling, Jacque, Wanggaard and cosponsored by Representatives Ballweg, Thiesfeldt, Petersen, Tusler, Wichgers, Subeck, Dittrich, Skowronski, Brostoff, Schraa, Horlacher, Kulp, Quinn, Loudeneck, Rohrkaste, Sinicki, and Bowen.

Hello, I am Mark Pepoy, my wife, Jennifer, could not be with us today. Thank you for allowing me to speak about our experiences. I am always happy to talk about our kids.

We are residents of the Village of Oregon. Jen and I are both members and volunteers with Bereaved Parents of Madison (BPoM), a local non-profit that supports parents of perinatal and infant losses.

On November 5<sup>th</sup> 2009 Jen was 19 weeks pregnant with twins. She attended an appointment with her OB/GYN because she knew something was not quite right. During this appointment she learned that she was in pre-term labor and was immediately admitted to the hospital where we stayed over the next 2 weeks until our babies were born.

A miracle was not to be. On the morning of November 14<sup>th</sup> at 20w 5d, both twins were showing steady heartbeats when full on labor began. There was no more denying that Matthew would be born. He was active moments before delivery. In an attempt to save the second twin, Thomas, the doctor delayed delivery which resulted in Matthew dying during delivery-a stillbirth. As sad and terrifying as the moment was it is still sacred to us. In the same moment we said "hello" and "goodbye". Luckily, once Matthew was born contractions stopped and Thomas remained safely in utero. Grieving for one child and holding out hope for another is gut wrenching. But that was our burden and there was no thought to shirk it.

Our Thomas was born exactly one week later at 21w 5d. He was born alive and was held in our loving arms for every one of the 42 minutes of his life.

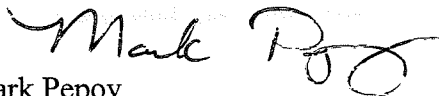
Although they were born only one week apart, their experiences in this world were very different. Having not taken a single breath, Matthew only had a blessing; Thomas was baptized as he was born breathing. Matthew could have had a memorial service; Thomas

a funeral. For Matthew there was no birth certificate, SSN and no Federal tax credit as he did not take a breath; all of those were available for Thomas.

A perinatal loss is a life-long grieving process. We are all grieving for the children we lost, the children we will never get to know and the dreams we had for them. No one expects to outlive their own child, then have to make decisions for them such as burial or cremation, coffin or urn, to have a funeral, memorial service or not celebrating your child. Jen did not plan on spending 17 days on strict hospital bedrest in an attempt to save our children. We did not plan on the financial cost of 17 days of hospital care including two deliveries, emergency surgery following the delivery of Thomas, the two months of lost work to allow for physical and emotional recovery, the cost of a funeral and two urns, the burdens both financially and emotionally of autopsies versus possibly knowing what caused our babies to die, the years of therapy.

Senate Bill 114 offers support to grieving parents to help offset the cost of an unexpected death of a baby who did not take their first breath. It also acknowledges that stillborn babies are still born. I still miss Matt and Tom every day. My wife and I will not benefit from Senate Bill 114 but advocate for it for those families that will face this. In the future, each year hundreds of Wisconsin families may have a bit of the financial burden relieved which can allow the grieving process to continue and the baby loss journey traveled with one smaller mountain. It will also allow some families to feel peace in their hearts knowing that their stillborn baby was recognized as a baby, a baby born sleeping.

With sincere appreciation,



Mark Pepoy



Wednesday, December 18, 2019

1:01 PM

201 Southeast

Testimony in Support of S.B. 114 for the Senate Committee on Agriculture, Revenue, and Financial Institutions.

Good Afternoon,

My name is Brian Czech, and I'm a resident of Monona, Wisconsin. I'm here today to express my support of Senate Bill 114.

In March of 2017, my wife Beth became pregnant for the second time. Our first pregnancy had ended four months earlier in the emergency room at 8 weeks along after we found out that it was ectopic. We were excited to be trying again, and looking forward to our future. For five and a half months, the pregnancy proceeded normally. Up until the last day, there was never any indication that anything was out of the ordinary.

While the rest of the Madison was viewing the solar eclipse of August 21, 2017, we went to the doctor and learned that our baby no longer had a heartbeat. Beth was induced that day, and gave birth to our son Calvin B Czech two days later.

In many ways, Beth and I were very fortunate. Calvin's birthday was one of the best days of our lives, despite the horrible outcome, thanks to the guidance we received from a volunteer of the Bereaved Parents of Madison peer support group, and the support of the staff at St. Mary's Hospital. We were lucky to have a high quality health care plan and employers who gave us each two weeks of paid leave. By chance, we selected our local funeral home from a list given to us in the hospital without knowing that they provide basic services and cremation free of charge to parents who lose a young child. Thankfully, we live in a city that has a well-established peer support group, the Bereaved Parents of Madison, that has helped us navigate our grief and heal in the months and years following our devastating loss. Many grieving families around Wisconsin are not as fortunate with their healthcare and funeral costs, or have supportive employers and convenient access to free support groups.

We still had many expenses, and financial pressure colored some of our decisions. We had a nursery full of baby gear, and had made several deposits at local daycares. There were hospital bills even though we didn't get to take our son home. My wife was out of work for two months on short-term disability at 60% pay, but I went back to work after

two weeks because the bills didn't stop just because life as we knew it did. I went to a couple of counselling sessions, and Beth saw a therapist weekly for almost a year. We never even considered a funeral or burial after seeing the price sheet. Instead, we had a remembrance cookout in our backyard, and our son resides on a dresser in our bedroom in a walnut urn I made for him. In total, we incurred about \$2700 in medical and funeral costs and lost wages.

It is hard to describe what the experience of losing an unborn child feels like to someone who hasn't experienced it. The fog of anger and sadness and grief and uncertainty about the future lasts for months. Your mood changes from one minute to the next. You feel overwhelmed by simple choices and tasks at a time you often have to make important decisions. You feel so incredibly isolated. This person who was so real to you, who is your child, is just an abstract concept to nearly everyone else in your life. Many expect you to move on quickly, to get over it. Some give you unhelpful platitudes. Some avoid the subject because they don't know what to say, or worse, avoid you entirely. They don't understand how desperately you want your child to be acknowledged. How important it is that people know that your child was alive, and was born, and was a person who existed.

Several weeks after Calvin was born, at one of the lowest moments in my life, his "Certificate of Birth Resulting in a Stillbirth" arrived in the mail. This document that I purchased doesn't look like a birth certificate, and has four written reminders that it can't be used as legal proof of identity and isn't valid for identity purposes. It was and still is a reminder that the State of Wisconsin, like the federal government, doesn't consider my son to be a person, and that's a hard thing for me to understand.

According to the Annual Wisconsin Birth and Infant Mortality Report, Calvin was one of 291 children stillborn in Wisconsin in 2017. To the hundreds of families in our state affected each year, this proposed tax credit would be a great financial help at a time when they could really use the support. In the midst of their profound grief, it would alleviate some of the financial stress that factors into difficult funeral, health, and work decisions. More importantly, this credit would be an acknowledgement by the State of Wisconsin to parents of stillborn children that their children existed, and they mattered.

Thank you for listening, and for supporting Senate Bill 114.

Brian Czech  
6111 Bridge Road  
Monona, WI 53716

**SB114 Testimony December 18, 2019**

**Maggie Koch, Green Bay WI**

Senate Committee Members, thank you for the opportunity to share my story with you. My name is Maggie Koch I am from Green Bay, I am a daughter, sister, wife, nurse, friend and most importantly a mother to my heavenly daughter Olivia Grace.

Today am I am here; along with my husband Brad share our support for senate bill 114 in honor of our daughter's very beautiful but short life.

Just a mere 3 days after my 30th birthday, May 20, 2019 was the worst day of my entire life. My pregnancy was normal from the very beginning, 3 weeks before I delivered, I had an ultrasound and everything was great, Olivia was growing and her heart was beating strong. When I arrived at my doctor's office that Monday morning I was 39 weeks and 5 days pregnant I wanted my physician to check things out because I had started to go into labor and being that this was my first pregnancy I wasn't sure what to expect. I didn't know if I should be admitted to the OB unit yet, so I went in to get checked out. It was at this visit they were unable to hear her heartbeat and told me Olivia had died. Hearing those words for the first time I thought I was living in a dream, this couldn't be, everything was fine just weeks ago, I just finished organizing her nursery the night before, I was healthy. I had a future laid out in my mind how our family of three was meant to live and that was only going to be a dream and not our reality.

I delivered Olivia that evening and held her in my arms admiring how simply perfect she was, every last inch of her was stunningly perfect. In that moment, my heart was shattering into a million pieces but at the same time, I was so proud and full of love for my sweet little angel. The next hours and weeks were a complete blur and excruciatingly painful. Those initial days so many decisions had to be made, every detail of her funeral had to be decided upon. Whether or not to cremate, what type of urn we wanted, what her obituary would say, the type of flowers we wanted, what pictures of Olivia we wanted to share with our family and friends and the list went on. We were very thankful for our families support to help us make these decisions with us and carry some of that weight.

As the weeks passed and grew into months and the raw pain of reality set in there were multiple doctor visits trying to understand what happened, visits with my counselor just to help me process the biggest tragedy in my life. I soon found out that the second half of maternity leave is not guaranteed so I had to jump through extra hoops to try to get additional time off, as I had no idea how I could function in the normal world carrying my heartache and the weight of my grief. Thankfully, I was able to use EBB allocation for the remainder of the 6 weeks, which I know is the case for all parents.

While there were many additional expenses that added up, paying my medical bills was a very common monthly expense, one in which I continue to pay. While the benefit of the tax credit would most definitely help relieve some of the financial burden, it is not solely about the money. This is important to me because I feel like it allows parents of a stillborn child to feel like their



child's life is validated and recognized by the state of Wisconsin. Recognized as a child that is, and always will be loved by a family and not just a number, not just a stillborn child. Supporting this bill to me says that my child's life and other stillborn children's lives are important and they matter.

I stand here today as Olivia's mom in support of SB 114 and encourage you to think about my daughter and the other children who have been taken from their families too soon and support the bill and those families left living with their daily grief.

Thank you for your time.

Maggie Koch

Out of Pocket Expenses  
 WI Stillbirth Family – Real Life Example  
 Maggie Koch  
 Green Bay, Wisconsin

Expenses	Cost
Urn	\$500
Cremation	\$150
Prayer Cards	\$80
Guest Book at Service	\$25
Weekend Funeral Church Fee	\$400
Clergy	n/a
Funeral Home Transportation	n/a
Flowers	\$480
Music	n/a
Thank you cards	\$120
Birth Certificate Resulting in Stillbirth	\$30
Death Notices –Newspapers	\$100
Counseling	\$400
Unplanned Emergency Expenses	\$4,800
Photo Prints for Wake	\$100
Photo Display boards & Supplies	\$300
<b>TOTAL</b>	<b>\$7,485</b>

**Considerations:**

**Basic Funeral Services Cost \$1,415 however the funeral home we used does not charge for infants.**

**Our church provided the music at no additional cost.**

**Clergy charge was a part of the weekend funeral cost.**

**I was able to get EBB benefits from my employer to cover the last 6 weeks of maternity leave; however, I know this is not the case for everyone.**

Amanda Smyth  
N69W23802 Donna Drive  
Sussex, WI 53089  
December 16, 2019

Agriculture, Revenue and Financial Institutions Committee  
State Capitol Building

Dear Committee:

I am writing to you in support of Senate Bill 114; the one-time tax credit for families who have experienced a stillbirth. My son Johnathan was born stillborn on February 3, 2015 at 28 weeks gestation. He was my first pregnancy. I am and was a healthy person with very low risk and yet something I thought only happened in the 1800s or to unhealthy people who made bad choices happened to me. I have lived the statistic of one in every 160 births ends in stillbirth. We were lucky enough that our funeral home was willing to do the funeral and cremation free of charge; we only paid for his urn. However, the healthcare costs we endured were high, only to come home empty handed. I went through birth just like every other mother who delivers a living baby but didn't get to bring my baby home. My husband and I both spent years in therapy trying to recover from the trauma of losing our son Johnathan. Almost 5 years later, I have adapted to my 'new normal' but continue to find ways that Johnathan's loss affects my life in ways I never expected. I am forever changed as a mother, a wife, a woman, and as a member of society.

Since losing Johnathan, I now volunteer my time as the co-chair for the Wisconsin Chapter of the Star Legacy Foundation which aids in my healing by helping other families who are experiencing the same type of loss. As an organization we are dedicated to stillbirth research, awareness, education, advocacy and family support. So many families would benefit from this tax credit. Not only would the credit help off-set the costs of medical expenses and funeral arrangements, the recognition of their child's life who could have potentially survived if medical care was different is critical. I hope one day this tax credit won't be needed. I hope one day stillbirth will be a word of the past, but until then it is imperative that these families and their children are recognized similarly to their counterparts that take a breath post birth. Please, I urge you to consider passing this bill and recognizing stillborn babies and their families. Thank you for your time and consideration.

Sincerely,

Amanda Smyth

Co-Chair, Wisconsin Chapter of the Star Legacy Foundation



Emily Grorud  
502 Piper Dr.  
Madison, WI 53711

December 18, 2019

Agriculture, Revenue and Financial Institutions Committee  
State Capitol Building

Thank you Mr. Chairman and members of the committee for having a public hearing on SB 114 today.

I am here to ask you to vote in favor of Senate Bill 114.

I joined the peer grief support group Bereaved Parents of Madison in 2010 after our baby boy was stillborn at 23 weeks 5 days gestation. It was our first pregnancy. We had wanted a baby for over two years and were so excited to learn we were expecting. This baby was much anticipated by his parents, grandparents, uncles, aunts, and cousins. Late one night I woke up with severe cramps, which I thought was indigestion. I couldn't sleep so decided to get up and do some work. My water suddenly broke. I was only 23 weeks pregnant. After rushing to the hospital we discovered I was in labor and they couldn't stop it. Our first baby, our son James Robert was born via emergency c-section. He never took a breath. He was stillborn. We held him, rocked him, and sang to him. We took pictures. Our family came to meet him. He was loved more than you can imagine. His early arrival was diagnosed with the vagueness of unexplained pre-term labor. He would have recently passed his 9<sup>th</sup> birthday.

We had a full Catholic service, luncheon, and burial for our son. We are fortunate to have excellent medical insurance, and the funeral home was fantastic in the fees they waived. I was working as a seasonal worker at a warehouse that fall and did not qualify for sick time or short-term disability despite having had a c-section. I was told in order to maintain my job, I had to go back to work. So 2 ½ weeks after having had major surgery of a c-section and burying our son, just as soon as I had clearance from my doctor to drive, I started back at work. In that 2 ½ weeks I was off, I was not compensated for my hours. Our out of pocket expenses including my lost wages was roughly \$2500. Since James was stillborn we did not qualify for a deduction on our taxes.

James was not our only loss in that 12 month span. 11 months after James' stillbirth we had a baby girl born at 24w4d.

Josephine Anne (or Josie as we call her) was born alive after nearly 2 weeks of hospital bedrest and an emergency c-section once again. Again, the vague diagnosis of unexplained pre-term labor haunted us. Unlike James, Josie was born alive and spent her 4 day life in the NICU before passing away of a severe brain hemorrhage. We once again had a full Catholic service, luncheon, and burial for her. Our out of pocket expenses added up to \$1200. My husband and I filed our joint taxes in 2011 with our daughter as a deduction, as she had been born alive. That year we saved nearly \$2000 (\$1970 to be exact) by deducting her as our child.

My children were 6 days apart in gestational age. They both died due to complications of prematurity. The only difference is one breathed outside the womb for a time and the other did not. My son, who was stillborn, ended up costing \$1000 more than our daughter. I was 28 years old, had said goodbye to both of my children, and had planned two separate funerals and burials. My children were born 8 and 9 years ago, my family will not benefit financially from passing this bill.

In addition to being James and Josie's mom, I'm also the treasurer for the 501c3 Bereaved Parents of Madison, Inc. We are a Madison area support group that was established in 1974. We support families experiencing the death of a child in pregnancy or infancy. We have over 400 members. We primarily serve Dane County but we have expanded to serve patients at Monroe Clinic Hospital in Green County and Sauk Prairie Hospital in Sauk County. If a patient delivers in Madison, but is from another county, we also continue to support them. Thus we do have members from many counties including Rock, Columbia, Dodge, Iowa, Jefferson, Outagamie, and La Crosse. The group has monthly support meetings at SSM Health St. Mary's in Madison as well as an online support page where parents can connect any time of day. In addition to support groups, we also offer programs for moms and dads, a book club, a December remembrance service and other family events that allow bereaved parents to grieve in a safe space. We recently had our December Remembrance Service and 194 babies' names were read. Bereaved Parents of Madison, Inc. also has a support group for families pregnant again after loss, to help them through the many emotions of expecting again.

We also offer a bedside support program called HUGS, which sends "veteran" bereaved parents to the hospitals to support parents during the loss. Our volunteers help guide families through the experience and to let them know that it's okay to take pictures, to bath your baby, to dress them and to hold them as long as they're able. Volunteers help families make a lifetime of memories in a short period of time. I personally facilitate our monthly support group meetings, and I am a HUGS volunteer. I have heard hundreds of loss stories and I have personally supported many families grieving the death of their baby. These are the families who this bill could benefit, and the families who we will be supporting in the future.

My two children, born 11 months apart. I gave birth by c-section to both of them and had the same physical recovery. One was recognized by the state as my child with a birth certificate and a child tax deduction. The financial burden is great after having a baby, arguably even greater when you are suddenly and unexpectedly planning a funeral and burial for your newborn child. We did not go into pregnancy thinking our baby would die. We were expecting to bring home a happy, cuddly bundle of joy. Planning a funeral and burial was never in our plans when we got pregnant. The tax deduction would help many families much more financially burdened than we were. But, more than that, I urge you to please vote in favor of passing SB 114 as an acknowledgement by the state that our child, our son, was born.

Thank you for your time today,  
Emily Grorud

## Acosta, Miranda

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**From:** Julianne Withers <jeepegirl74@yahoo.com>  
**Sent:** Tuesday, December 17, 2019 5:49 PM  
**To:** Keith, Rachel  
**Subject:** WI Stillbirth Tax Exemption Legislation

My name is Julianne Withers and I live in Madison. I have lost four pregnancies, 2 were early and 2 were in the second trimester. The first one happened so quickly and brought me to make an Incompetent Cervix Awareness page on facebook 12 years ago which now has over 9000 members worldwide. This means that my cervix painlessly dilates and that baby comes out quickly and too early. This first loss in 2005 was at 16.5 weeks and I asked what could be done with the baby and they said they would just throw him out with the medical waste. (These losses were all when I still lived in Michigan.) I asked for a phone book and got a funeral home to get him and arrange cremation at my expense.

The third pregnancy was viable and I started bed rest with a stitch holding my cervix closed at 15 weeks. At 23 weeks and 1 day, he came into the world at 1 lb 9 oz and lived for 8 days in March 2007. Luckily we did qualify for a tax credit because he lived because between the funeral (over 20 weeks in Michigan means a need for proper disposal after demise) and the time lost for work, therapy, death certificates, thank you notes, etc etc it was probably a \$6000 expense. We also had him cremated but did not opt for the more expensive burial and headstones.

My perspective is a bit different as I did not have a stillborn. My perspective is how wonderful it was to have some of our costs defrayed by even a small amount. This is why I feel families should be able to get assistance. Thank you for listening to us. We appreciate you.



**Public Hearing  
December 18, 2019**

**Committee on Agriculture, Revenue and Financial Institutions**

Senate Bill 114 Relating to: creating a refundable individual income tax credit for the parent of a stillbirth.

Good Afternoon. Mr. Chairman and members of the committee, thank you so much for scheduling this hearing. We're grateful to Senator Darling and her staff for working so hard on this legislation. And I want to thank Senator Jacque on this committee for his co-sponsorship. My name is Rebecca Markert, and I am here to ask you to vote in favor of Senate Bill 114. I live in Verona, Wisconsin, with my husband, Michael, and our four living children.

We joined the Bereaved Parents of Madison support group in 2010 after my first pregnancy ended in stillbirth. Our daughter, Lily, was born still after I went into preterm labor at 20 weeks and 1 day gestation. When I was admitted to Labor and Delivery on Mother's Day morning in 2010, Lily had a strong heartbeat – 144 BPM – and we were hopeful that the doctors would be able to stop labor and we could buy some time until she could survive outside my body. We needed to make it 4 weeks to have some chance at viability and a better chance for her to survive as a micro-preemie. The intervention did not work, unfortunately, and she was born without a heartbeat at 9:30pm that night. She died during labor.

Losing our first baby shook us to our cores. We were shocked, sad, angry and suddenly faced with decisions that no young, newly married couple should have to make. We were asked if we thought about whether we'd like our baby to be buried or cremated. We

hadn't made those plans for ourselves much less gave it any thought for our baby. Do you have a funeral? A memorial service? Where do you even buy an urn? These are things we had to talk about hours after delivering our baby.

I missed work for two weeks. I thought I was ready to return. Ready to move on. But then I realized the fog of grief was so thick that I couldn't concentrate. My focus lasted a mere 3-4 hours at best – and even then it wasn't the best focus. Eventually, I reduced my hours to part-time until I was in a better place. Unfortunately, that really ended up being until I absolutely needed the full-time salary again. My husband had returned to school before our daughter was born and we were one income household.

I saw a grief counselor – almost every week in the beginning. Then every other week, then every month. For over two years. My husband came with initially but as everyone grieves differently, it wasn't until 5 years later that the trauma from the stillbirth affected him so greatly that he needed to seek treatment. Five years later, we were still enduring healthcare costs from the birth of our stillborn daughter.

We didn't have a funeral for Lily. We had her cremated and spent months trying to find the perfect urn. Originally, we were told the funeral home would provide one but they only provided a white, plastic box with a label on it. It resembled a box for crime evidence more than the final resting place for our precious baby girl. We were eventually gifted an urn, and she rests on the nightstand next to our bed.

We decided to approach Senator Darling and Representative Ballweg about this proposed legislation because we've met so many bereaved families who have experienced astronomical costs associated with the deaths of their babies. While we didn't have a funeral, and my health insurance is a so-called Cadillac plan, many of our friends were not so lucky. Families spent 1,000s of dollars on medical bills, funeral costs, gravestones, counseling and more all in the aftermath of the worst tragedy you can experience – the death of a child. You've heard from some of those families directly today. Every year in Wisconsin, almost 300 babies are born sleeping. Almost 300 families every year join this club no one wants to join.

It's now been almost 10 years and I'm still involved with our local support group. I can attest that every year at tax time a newly bereaved parent in our group poses the question "can I claim my baby on my taxes?" Significant "life events" are important when reviewing your taxes from the previous year. The birth of a baby is one of those events. The question "did you have a baby this past year?" is one of those questions that for a bereaved parent has a complicated answer. And it's very emotional. Yes, I did have a baby in 2010. But no, she never took a breath. So she doesn't count.

Tax time is as much an emotional trigger for grieving parents as asking the question "how many children do you have?" But harder because it's unexpected. You expect to be sad on their birthdays, at holidays like Halloween or Christmas, or on their due dates. You don't expect to be triggered for grief while doing your taxes. Every year it happens. Every year some family is heartbroken because they don't get to check that box yes.

If their baby had lived, even for a short minute, they'd be eligible for a child tax credit. And this inequity shows every year. Some of the parents we support get to claim their baby. Some don't. Some have a twin who lived for a day or two and the other twin was stillborn. They get to claim one but not the other. It's confusing to parents. It's heart wrenching and painful to explain to them the difference in the tax code. And it's unfair.

For our families it's not about the money. Obviously, \$2,000 is a nominal amount when looking at the amount families actually spend to bury their children. This bill is also about acknowledging our families who go home empty-handed. It's about letting bereaved parents know their babies mattered. When you lose a very much wanted baby in pregnancy, you spend a lot of time trying to affirm their existence. You want people to know they lived and that they mattered. This bill would help bring the acknowledgment bereaved parents desperately crave.

Finally, my family would not benefit from this bill if it were passed into law. We urge you to vote year on this bill on behalf of the families who've experienced stillbirth this year, and who we will be supporting in the future. Please give grieving families the comfort and financial security they need by passing this legislation.

Thank you.

Remarks given in person by:

Rebecca Markert

746 Grace St.

Verona, WI 53593

## Acosta, Miranda

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**From:** Bereaved Parents <bereavedparentsofmadison@gmail.com>  
**Sent:** Wednesday, December 18, 2019 12:46 PM  
**To:** Keith, Rachel  
**Cc:** Rebecca Markert  
**Subject:** SB114 Statement from Bereaved Parents of Madison, Inc

Committee on Agriculture, Revenue, and Financial Institution,

It is with great disappointment that I can not be present at the hearing today regarding SB114. I'm a representative from the Bereaved Parents of Madison, Inc. We are a Madison area support group that was established in 1974. We support families experiencing the death of a child in pregnancy or infancy. The group has monthly support meetings at SSM Health St. Mary's in Madison as well as an online Facebook support page where parents can connect any time of day. In addition to support groups, we also offer programs for moms and dads, a book club, a December remembrance service and other family events that allow bereaved parents to grieve in a safe space.

In 2015, we expanded our programs to include a bedside support program called HUGS, which sends "veteran" bereaved parents to the hospitals to support parents during the loss. Our volunteers help guide families through the experience and to let them know that it's okay to take pictures, to bath your baby, to dress them and to hold them as long as they're able. Volunteers help families make a lifetime of memories in a short period of time. These very special volunteers are active at SSM Health St Mary's Hospital Madison, Unity Point Health Meriter, Monroe Clinic, and Sauk Prairie Healthcare

I joined BPOM in 2010 after the stillbirth of my twins James and Sophia at 22 weeks and 6 days. They were absolutely perfect in every way, just born too early to survive on their own. Our time with them was brief and confusing. We attended our first support group meeting the very next day and struggled to tell the other parents what we had just experienced the day before. Finding peer support was so comforting and powerful.

In the 9 years since I've joined the group, and especially since I became President of the group 4 years ago, I've supported many families who've experienced stillbirth and I'm intimately familiar with their babies stories. Many of these families have relayed information about the expenses the incurred after losing their children. In addition to the ones you've heard today, we've heard expenses up to thousands of dollars. I would like to briefly share a few with you:

Family 1:

Lisa Volkman joined our group after the stillbirth of her son Landon at 8 months gestation. Lisa shared with me that she incurred the following expenses: Medical costs: \$1,500, Funeral \$500, Counseling: \$2,000, So \$4,000 total out of pocket.

#### Family 2:

Another family, the Olds, joined our support group in 2010 after their daughter Finnley was stillborn at full term. She shared with me:

- Funeral cost \$500 out of pocket.
- She was allowed to take short term disability from her job for 6 weeks at 60% pay. She estimated that she lost \$1500 in wages during that time. There is no maternity leave when you deliver a baby stillborn, even though you carried the baby to term. FMLA also does not recognize stillbirth.
- She also paid for \$75 worth of therapy session copays.
- For a total of \$2075

#### Family 3

Liz Green shared with me: "In our situation, with Ruby's complications, we had \$2,500 in medical expenses before delivery, then the birth was another \$1,500. And this was with employer sponsored health insurance. We paid \$4,000 in medical expenses, and left the hospital with a box, instead of a baby. We then paid another \$4,000 for funeral flowers, a casket, and a headstone. We are fortunate to have jobs that allowed us to afford these expenses without putting us under, but many are not so fortunate." A total of \$12,000 out of pocket.

#### Family 4

Finally, I am going to share with you what Rachel Karls shared with me about her son Dean's stillbirth.

"Our total [medical] bills were around \$9,000, and we paid about \$5,000 out of pocket. The bills just kept coming in it felt like weekly, and thankfully Tyler handled all of it, because each time we received one it was just another kick in the gut on top of losing our son. All of this of course was while I had to take leave from work/only go back part time because I couldn't handle anything more than that. We were very blessed that the funeral home the hospital contacted for us did the cremation service free of cost, otherwise that would have been an added expense. There have been therapy bills too on top of those costs, but what they are exactly I'm unsure."

These families give just a sample of the parents we have supported locally. Outside of Dane County it's often more expensive for a funeral. I talked with Olson Funeral Home in Dunn County and families can expect to pay \$1280-1775 for a burial and related products such as a casket and obituary. In Green Lake County, I spoke with Wiecki-Skipchak and discovered they could expect to spend \$1440-1880 for the same burial services and products.



Another local nonprofit Babies Gone Too Soon located in Grant and Iowa counties helps families with some of these expenses. The most common request for support is for funerals and can range from \$700-1500 per family.

- There is NO life insurance to pay for medical and funeral expenses.
- Autopsies are not covered.
- There is NO paid maternity leave or FMLA coverage.

This bill is also not just about the financial hardships that losing a baby can put on families. It is also about acknowledging the loss of a life. It is very powerful when someone pays attention...

I hope that you will consider supporting this one time tax credit for families who experience a stillbirth in the future. It would NOT have a huge impact on our state's budget, but it would have a significant impact for these families.

Thank you for your time.

Respectfully,  
Claire J Matejka  
Mother of James and Sophia  
Born Still February 17, 2010

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Claire Matejka  
President, Bereaved Parents of Madison Inc  
Call 920-643-0217  
Email [bereavedparentsofmadison@gmail.com](mailto:bereavedparentsofmadison@gmail.com)  
Web [www.bereavedparentsofmadison.com](http://www.bereavedparentsofmadison.com)  
Facebook: PUBLIC Bereaved Parents of Madison Inc

[Sign up to receive our Monthly Support Calendar email of events.](#)

The Bereaved Parents of Madison, Inc. is a support group for parents who have experienced the death of a baby from conception to approximately one year of age. It was started by parents who felt that no one should have to go through this difficult time alone. Services are provided free of charge by parent volunteers. Bereaved Parents of Madison, Inc. is a 501(c)(3)

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My name is Jenn Streator and this is my husband, Geoff Streator. We are from Sun Prairie, Wisconsin. We are here to share our daughter's story with you. Her name, is Lucy Jane Streator.

After 3 years of fertility treatments and surgeries, we found out that we were pregnant on March 21, 2017. We were over the moon excited and in love with our little Nugget. We had the usual ultrasounds and everything was perfect. We soaked up every moment. We went on weekly hikes and took the weekly bump pictures. Nugget loved our hikes the most. Within the first half mile, she would settle into the bottom of my belly and ride out the miles.

As the pregnancy progressed, so did our plans. The nursery was ready. Clothes were purchased, washed and folded. We picked a daycare and reserved her spot.

On November 11, 2017, we went to St. Mary's Hospital in Madison for a check up because I could tell something was not right with the pregnancy. My spirited little kicker was not kicking as much. This was a Saturday, the Badgers were playing at Camp Randall. It was the Veterans Day Game. I will always remember scrambling to find the game on TV to try to have anything, anything, to focus on other than the reason why we were there. The F-16s flew over at 3pm. At that time, we learned that our Nugget had died.

My body had already started labor – it knew. It was trying to help. I was 36 weeks and 6 days pregnant. By 9pm I needed an epidural. By 10 pm I was fully dilated and needing to push. Our nugget was born at 1:21 am on November 12, 2017. She was 5 lbs 2 oz and 18.5 inches long with a head full of long brown hair and confirmed that she had big feet for kicking. Geoff announced that it was a girl, and we chose to name her Lucy Jane. Lucy, like Lucy in the Sky with Diamonds. We stayed in the hospital until Tuesday, thanks to the Cuddle Cot to keep her body cool. Family and friends got to meet and hold Lucy. We took pictures. We watched the Packers beat the Bears. We read to her and sang to her. We did all we could until it was time to say goodbye.

We decided to have a funeral for her because we honestly just didn't know what else to do. It turned out to be one of the most amazing days of our lives. Around 100 people came to meet and love on Lucy and us. We sang Puff the Magic Dragon to her, laughed, cried, and were enveloped in love. We buried Lucy in the City of Sun Prairie Cemetery. We bought our cemetery plots right next to her at the same time. She rests a mile away from our home.

Neither Geoff or I were eligible for FMLA. I had to take off 7 weeks after Lucy's birth just to physically heal from labor and delivery. Luckily I had saved my PTO for maternity leave and my employer was flexible so we made this work. Even still, I think it is hard for people to understand why you might need substantial time off when your baby dies. If you've ever been in labor, you know that healing is not your timeline to determine. Geoff was at his employer for less than 6 months, so he was not eligible for FMLA either and he did not have much PTO built up. Luckily, his employer gave him 2 weeks paid time off. Had we been in different situations, I know we would not have been so lucky.

I would love to tell you more of our story. Of Lucy's story. I'm so proud to be Lucy's mom. We have found an incredible community of people through Bereaved Parents of Madison, Mikayla's Grace, and Faith's Lodge, many who are here today.

The cost of Lucy's life and death include:

\$500 hospital costs

\$80 funeral flowers

\$300 for a casket

\$1385 for a headstone

\$450 for a burial plot

\$855 for a celebration of life, including food and venue rental

\$297 for therapy programming /Faith's Lodge

\$179 for birth announcements that doubled as funeral thank-you's

The total for these items was \$4,106 after \$325 in discounts that we know of from a few of our local vendors who were very kind and generous.

Of course, there are more costs associated with Lucy's life, like her crib that sits empty and the clothes that were never worn. There are more costs associated with her death, like the review of her autopsy results from several medical professionals, and the costs that never have a true monetary value, like the hole in our hearts that exist because of her absence.

We believe it's important to support this bill because even though Lucy died, having this bill pass would acknowledge that she existed. Our fog of grief was so thick that looking back, I actually don't know how we paid the bills. Even the routine ones. We feel privileged to have found ways to pay for these unexpected items. We were privileged to have family and friends rally to feed us, to clean our house, to rake our leaves. Many parents do not have these privileges. I urge you to vote YES on senate bill number 114 to help all those who suffer the heartache of burying their stillborn baby the recognition that they lived and to ease of financial burden that is critical to surviving that first year.

Thank you.

Out of Pocket Expenses  
 Lucy Jane Streator (Jenn & Geoff Streator) – Real Life Example  
 Sun Prairie, Wisconsin

Costs

Hospital Costs	\$500
Casket/Urn	\$300
Headstone	\$1685
Headstone Discount	-\$250
Cemetery Opening/Closing	(waived)
Cemetery Interment Fee	(waived)
Burial Plot	\$450
Funeral Home Costs (transportation, embalming, service, etc.)	(waived)
Flowers	\$80
Funeral Reception Rental	\$150
Funeral Reception Rental Discount	-\$75
Funeral Reception Food	\$780
Thank you cards/Birth Announcement (photo on one side, thank you on other)	\$179
Birth Certificate Resulting in Stillbirth	\$10
Counseling	\$297
Total	\$4,431
Discounts	\$325
<b>Final Sum Paid</b>	<b>\$4,106</b>



I write to you to request that you support SB 114/LRB-1256, creating a refundable individual income tax credit for the parent of a stillbirth.

So often we are the “forgotten parents”; the ones who carried our children, planned and prepared for them, endured labor and delivery, but didn’t get to bring our children home with us. Our maternity/paternity leave was changed to bereavement leave, if we were lucky. My husband’s 10 weeks of paid paternity leave, turned into just 5 days of bereavement leave.

In addition to our unimaginable grief, we endure all the same postpartum symptoms and complications, but without our children smiling up at us. We didn’t receive birth or death certificates. We have pictures of our children, that many find difficult to look at, unable to share our children with others.

My daughter, Lillian James Ziegler, 7 lbs 3 oz, 20.5 in, born at 38 weeks, just one week before my scheduled C-section, on May 29, 2018, does not legally exist, although my heart and my body know otherwise. The differential factor in deciding legal “life” is if the baby took a breath outside of the womb. Because my daughter was already deceased when she was delivered, she didn’t receive a social security number, a birth certificate or death certificate. Despite being more than viable outside of my body, she is referred to as a fetal demise. My sweet little Lily only exists to my family.

This bill will help families like mine recover from the worst possible pregnancy outcome. Prior to my experience, I didn’t know babies could die in the womb without signs or symptoms of concern. Certainly there would be pain, bleeding, or some indication of their passing. My daughter died inside of me without me being aware of it. I had no complications, high risks, or major concerns during my uneventful normal second pregnancy. An autopsy was performed at Children’s Hospital and it was found that for unknown reasons, a blood clot formed in the umbilical cord and cut off her blood supply. I had extensive testing, including genetic testing, all of which were negative. I’ve had iron infusions every other day for 3 weeks, B12 injections, ultrasounds, lab work and countless doctor appointments with ob/gyn, hematology, psychiatry, psychology, maternal/fetal medicine and many other specialists. I’ve traveled to Madison several times for treatment at the Hope After Loss Clinic run by UW-Madison. Luckily, I have insurance and did not incur a large amount of medical bills; but not everyone is in my position and financially able to receive all the needed medical care that follows a stillbirth.

So far in 2019, I have accumulated over \$32,000 in medical bills just for myself. Luckily, I was not responsible for that full amount due to my insurance coverage through my employer. In 2018, since the date I delivered in May, through the end of December, I accumulated over \$42,000 in medical bills, not including the actual delivery or any bills prior. I was off of work on unpaid FMLA leave for 12 weeks in 2018 immediately following the delivery. I am currently off on unpaid FMLA leave for grief therapy and mental health treatment. In 2019, I underwent hysteroscopy surgery and a D & C to remove scar tissue from my uterus. I have encountered secondary infertility, which was never previously an issue with my prior pregnancies. I elected for conservative treatment and underwent 3 months of ovulation inducing medication, due to it being the least invasive, and the least expensive. If I do become pregnant in the future, I will likely face much closer supervision, increase in diagnostic and surveillance testing and possibly more hospital time. I find myself in a situation where it is best for my health and wellbeing to not work full time, however; I’m forced to need to work to maintain my superior insurance coverage due to all my ongoing medical conditions and treatments.

The impact of a stillborn child affects far more than just the parents. My 6 year old daughter struggles with her emotions and understanding of her little sister that never got to leave the hospital. She is having some difficulty with starting kindergarten, and is fearful that something will happen to my



husband and I. I anticipate that losing Lily will continue to be an event which my family will need to seek medical assistance with for the rest of our lives.

My life is forever changed because of my daughter, Lily. This tax credit will lessen the burden for those who unfortunately find themselves in my similar situation. Money should not dictate how a family chooses to lay their baby to rest. Supporting this bill will let parents of stillborn children know that their baby existed, that their baby counted, that Wisconsin cares that they had a child, and that their child died.

Thank you again for making a lasting impact on fellow loss families and for not forgetting us as parents.

Sincerely,

Melissa Ziegler  
Menomonee Falls, WI

Agriculture, Revenue & Financial Institution Committee – SB114  
Public Statement by Tina Keller  
December 18, 2019

My name is Tina Keller, mom of Shea-Tate. Thank you for giving me this opportunity to share my story & why I support Senate Bill 114. I live in Milton with my husband Matthew and my 3 living children (John, Colby & Cypress). My journey here to you today began in 2005. I was pregnant with our 3<sup>rd</sup> child when at my 20-week ultra-sound cysts were identified. With this a new journey began and our son was diagnosed with Trisomy 18. Which means he had an extra #18 Chromosome in all of his cells. An individual with Trisomy 18 will have many medical problems along with severe mental retardation. I had an 80% change of a miscarriage or stillbirth. There was a 30% change if born alive he would live for a month and only a 10% change he would live for a year.

When we heard this we began to grasp at anything that we could to help guide us. I spent hours on the phone & in the office with my dr. trying to understand what was put in front of us. We were given our options but still were lost. Then my Perinatologist said to me, "Tina your baby is going to die. He may die inside of you, he may die at birth...but he's going to die!" And with that I knew it was time to just celebrate him. We decided that we did not want any extraordinary measures taken at his birth and decided to deliver in Janesville. For me I felt like the safest place for my son to die was inside of me, surrounded by our love.

We had created a birth plan for his angel day and with the guidance of our doctor & nurses his day was peaceful. I was blessed to carry him for 33 weeks & on September 21<sup>st</sup> he was born a tiny 2 pounds 13oz and was 15" long. We spent the day singing, reading and just hugging him up. We sang Happy Birthday & baptized him too. Never once throughout the day did anyone treat him like he was dead. Our sons even fought over holding him & added humor to the day. He has two first names because John & Colby named him. The day was everything we had hoped and planned for as we only had 13 hours to create a lifetime of memories with him. We had never experienced anything as beautiful yet so sad. As the day came to a close we needed to say goodbye and it was the hardest thing we had ever done. It truly was the hardest part of the day.

Leslie was our nurse during the actually delivery and she came in the next day and said, "Thank you for allowing me to be a part of something so beautiful." For me that was so important because I had just met her and she able to see the beauty I wanted for my son's birthday. A couple of years ago, I saw her again when speaking at a luncheon at Mercy Hosp./Clinic and she told me..."Tina, you taught me how it could be done." My heart was full!

Later the next morning brought more sadness when we were told that we were not going to get a Birth Certificate but a Certificate of Birth resulting in a Stillbirth. It was the moment our son was not recognized as a person in the State of Wisconsin. ***This*** very moment is what motivates me to do what I do...it's why I am here today.

Through this journey we had countless doctors appointments, additional testing and counseling. The bills piled up. The burial of our son alone cost \$3683 & he was just a tiny 2 pounds. I even struggled with the insurance company paying for the delivery because I was told, "It wasn't actually a birth".

I'm here today with other from the Bereaved Parents of Madison. We are a close group of 300+ parents who have lost a child.

I'm asking you to support this bill. Please vote YES for these babies & their families. Recognize them as a PERSON. Giving a family this small break can alleviate some of the financial burdens they will face. It can & will give them HOPE to find some peace beyond the very unique sadness.

Thank you!