Margaret Aeschliman Testimony SB891.pdf

Uploaded by: Aeschliman, Meg

Position: FAV

I am writing as a mother who has gone through perinatal hospice to urge your support for HB1112/SB891.

On January 5th, 2010, my husband Adrien and I were excited to see the first ultrasound of our first baby who was 12 weeks gestation. We went into the ultrasound room together, smiling and holding hands. A few minutes after the ultrasound was started, the technologist politely excused herself from the room.

A few minutes later, we were escorted into a small conference room where we were soon greeted by Dr. A, a perinatologist, who was accompanied by a team of medical students. Dr. A proceeded to tell me that our baby had a neural tube defect (anencephaly), that it was quite severe, and that the baby, if it made it to term, would not likely live past one year old. Receiving this information is a blur to me. When he asked if I had any questions, I asked him for a minute alone with my husband.

We briefly discussed our situation, and decided together that we wanted to continue the pregnancy, as long as my health was not put at risk.

When Dr. A. returned, he provided information regarding all of my termination options. He advised that early termination would allow me to conceive again sooner and we would be able to fulfill our dream of having a healthy child. I remember him saying, “this can all just go away”. Prior to this, I had been receiving care through a midwife. When I called to give her an update on my pregnancy, she never returned my calls.

A genetic counselor helped me to receive a second opinion ultrasound to confirm the diagnosis. I then made several appointments with various OBGYNs to discussed treatment plans.

I asked for counseling services, searched perinatal hospice centers, charitable organizations, and for the information of any woman who has been in a similar situation to provide guidance. Through months of individual research, I found a support system that halped to lighten the load.

We finally found the option of Gilchrist Perinatal Hospice and an OBGYN at Saint Joseph Hospital who was willing to work with our birth plan.

Our daughter did not go along with that plan. Because I continued to work through this pregnancy, I was Charge Nurse on an intensive care unit on May 5th when my water broke and contractions started. I was 31 weeks gestation.

Maria Grace was born a few hours later in the hospital in which I worked. Nothing went according to the plan that we had put together for months. Because of her poor prognosis at that gestational age, I signed a DNR for the baby. She was born and lived long enough for my husband and I to hold her. She was baptized.

Throughout the 5 months that I was pregnant with this terminal pregnancy many people asked why I had decided to carry my child to term. Though I was raised Catholic, the desire to carry the baby to term had less to do with Catechism and more to do with an instinctive need to let my baby live as long as possible and naturally reach her full potential. We knew the road would not be easy but we did everything that we could to make the best of the situation. It was a very difficult decision and the sadness of losing my first child affected me for several years. I have no regrets for carrying her to term. I'm so glad that I was able to hold her and know that I did everything that I could to help her to live her most comfortable life.

After my pregnacy, I was contacted by the Baltimore City Department of Health. They asked to interview me about my experience. I offered to provide that with the list of resources that I had found through months of searching during a very difficult time. I have not seen how these resources have been used or submitted. Having a page on the Department of Health website and brochures for doctors to give to families would help families going through a difficult time to be supported with sensitivity and compassion. My desire to provide help for any family in the same situation was real then, at it is now.

HB1112/SB891 would ensure no family is only offered termination, or left to find their own information regarding options, during a very difficult time. The best decision is an informed one. Families should feel the support of their health care providers and their Health Department for any choice that they make.

For these reasons, I urge a favorable report on HB1112/SB891.

Margaret Aeschliman
4008 Roland Ave.
Baltimore, MD 21211

What we have once enjoyed
and deeply loved
we can never lose,
for all that we love deeply
becomes a part of us.

--Helen Keller

2021.SB891.pdf
Uploaded by: Arlinghaus, Francis
Position: FAV

SB0891

Dr. Frank Arlinghaus

Favorable

Please issue a favorable opinion on Senate Bill 891. In order to be brief, I restrict my comments to perinatal hospice.

Perinatal hospice and palliative care is a relatively new field, proposed in 1997, and growing to over 300 programs worldwide, including at least 9 programs in Maryland. These include programs through Anne Arundel Medical Center, Chesapeake Kids, Gilchrist Kids, Holy Cross Hospital, Howard County General Hospital, Isaiah's Promise, Johns Hopkins Hospital, Shady Grove Medical Center, and SilverLeaf Counseling Services. These programs find wide support among the community of perinatal medical professionals, but are often not widely known among the general population.

These programs provide help for families to help continue pregnancies for lives expected to be brief (life limiting conditions), helping parents through this most difficult of times from the time of diagnosis. Too often, parents who experience an adverse prenatal diagnosis are not given adequate support or direction to resources that will support them. These programs give parents real help, real choices, and real support.

For some of us, the choice to terminate a pregnancy is unthinkable; for others, it doesn't seem like the compassionate choice under the circumstances. Without support or knowledge of the support, however, each of us feels limited in our options and pressured to make what we think is a bad choice. These programs, on the other hand, provide us the support to embrace the all-to-brief shining moments of parenthood, celebrating and grieving in their turn with the support of others.

This bill would ensure more parents experiencing an adverse prenatal diagnosis would be presented ith information to help inform and support them. For this reason, I ask that you return a favorable report on SB0891.

2 - FIN - SB 891 - BON - LOS.pdf

Uploaded by: Bennardi, Maryland Department of Health /Office of Governmen

Position: FAV

Maryland
DEPARTMENT OF HEALTH

Board of Nursing

Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Dennis R. Schrader, Acting Secretary

March 10, 2021

The Honorable Delores G. Kelley
Chair, Finance Committee
3 East Miller Office Building
Annapolis, MD 21401-1991

RE: SB 891 – Public Health – Maternal and Child Mortality – Review and Perinatal Hospice Services – Letter of Support

Dear Chair Kelley and Committee Members:

The Maryland Board of Nursing ("the Board") respectfully submits this letter of support for Senate Bill (SB) 891 – Public Health – Maternal and Child Mortality – Review and Perinatal Hospice Services. This bill authorizes the State Child Fatality Review Team and Maternal Mortality Review Program to enter into a certain agreement with an entity for certain storage of data and requires the agreement to provide certain protection and address certain issues. This bill further authorizes a physician or nurse practitioner who diagnoses an unborn child as having a certain anomaly to inform the pregnant woman in a certain manner of certain services, offer or refer the pregnant woman for certain services, and provide to the pregnant woman a certain information sheet. Additionally, the Maryland Department of Health is required to develop a certain list of certain perinatal hospice programs, and publish on its website certain information and a certain list.

The Board believes this bill to be beneficial to Marylanders by allowing the State Child Fatality Review Team and Maternal Mortality Review Program to safely and respectfully collect data. The collected data has a strong potential to improve maternal care and perinatal standards within the industry. Evidence-based medicine is crucial and exemplified within the practice of nursing. Data supports the adoption of best practices, which in turn are implemented into policy and procedures conducted by health care practitioners. Due to the sensitive nature of perinatal hospice care, it is crucial to collect, protect, analyze and publish up-to-date data to inform policy and practice changes.

Additionally, the role of a nurse practitioner is critical within the scope of perinatal hospice care. Nurses are taught to not only provide holistic care addressing the physical needs of a pregnant woman, but also to create and foster a supporting and understanding environment. After a nurse practitioner diagnoses lethal fetal anomalies, it is greatly encouraged that the appropriate services and information are provided to the pregnant woman.

For the reasons discussed above, the Board of Nursing respectfully submits this letter of support for SB 891.

I hope this information is useful. For more information, please contact Iman Farid, Health Policy Analyst, at (410) 585 – 1536 (iman.farid@maryland.gov) or Rhonda Scott, Deputy Director, at (410) 585 – 1953 (rhonda.scott2@maryland.gov).

Sincerely,

Gary N. Hicks
Board President

The opinion of the Board expressed in this document does not necessarily reflect that of the Department of Health or the Administration.

2021 March 5.pdf

Uploaded by: Capen, Alane
Position: FAV

Coastal kids
Supportive Care

40 YEARS
Coastal Hospice

March 5, 2021

Senator Mary Beth Carozza
James Senate Office Building, Room 314
11 Bladen St.,
Annapolis, MD 21401

Dear Senator Carozza,

I would like to voice support for senate bill 891 Public Health – Maternal and Child Mortality – Perinatal Hospice Services.

Coastal Hospice is a member of the regional Pediatric Alliance and serves terminally ill infants and children in Somerset, Dorchester, Wicomico and Worcester Counties. We have often provided perinatal support to parents when their child was expected to be born with a serious life limiting condition. Social Work and Chaplaincy are involved, and Nursing begins coordination early on to make a multidisciplinary plan with the obstetric care team. Our bereavement staff follow for 2 years after the death of the infant.

We applaud efforts to educate parents about available supports and we believe that bill 891 will have a positive impact on connecting parents to perinatal supports they need, and to hospice services for the infant for however many hours, days or months the family may have. This is such an emotionally charged time for parents and these are clinically complicated births, the obstetric care team needs to include the hospice that is prepared to support, coordinate, and participate in the process.

I do want to remind lawmakers that perinatal support is a free service done under charity care for which there is no reimbursement, but many hospices do gladly. We are reimbursed only for hospice care (defined by licensure) to the child once born.

Thank you for sponsoring this important bill.
Sincerely,

Alane Capen,
President
Coastal Hospice and
Coastal Palliative Care

Katherine Fitzgerald Testimony.pdf

Uploaded by: Fitzgerald, Katherine

Position: FAV

March 7, 2021

Finance Committee, Maryland General Assembly

Re: Testimony in support of SB891

Dear Honorable Members of the Maryland Senate,

I am writing this letter to share our family's personal experiences in receiving perinatal hospice care and support and how the need for this information and resource is of great importance to a family who receives that awful news and diagnosis. What should be their happy parent moment at their ultrasound appointment turns into a devastating shock. Our family has had the fortune and the unfortunate experience of two such fatal diagnosis and having to bury two children.

We have two healthy children who were ecstatic to bring a new baby into our family. We were told at 11 weeks, January 2016, that the DNA test showed we were having a boy and that Trisomy 18 was evident. We held hope until week 13 for his ultra sound yet his measurements and pictures only confirmed the bloodwork results. We were nervous, scared, and counseled that it would be the best to terminate. I remember asking questions about if our baby would survive to term and wanting to know about other options but not given much information or hope.

We were completely blown away and went home devastated. We are a Christian family though Lutheran, we do not abide by any strict demands regarding abortions. When it came down to it, my husband and I decided this was a child we wanted, planned for, and rejoiced at his positive pregnancy test. (I had a miscarriage at 8 weeks in the previous fall). I am in special education and down to the core it just did not feel ethical to end a life just because it was going to have severe needs, if even able to live past birth. My husband and I shared our commitment to our son when the genetic counselor called us back the following day.

As luck would have it, a new genetic counselor had come to the practice that we weren't able to meet with the day of our diagnosis. She was previously from Annapolis where she said families don't seem as pressured to terminate and choose to carry forth difficult pregnancies. She explained of a resource in Annapolis who ran a prenatal hospice program for parents. I never knew of such a thing. Our OBGYN was connected to Holy Cross Hospital (Catholic) which had such a program and our genetic counselor put us into contact with the nurse in charge. She arranged a meeting with us, the diagnosing doctor and the nurse in charge of the 'Never Alone' program. A program that tries to meet the medical and emotional needs of families birthing babies such as our son.

The meeting helped chip away at the mountain of questions we had and we received another program reference to Isaiah's Promise. They assign a mentor (a mother who has experienced a severe diagnosis and loss) to follow the mother and family through the *entire* pregnancy. The mentors help us plan the birth arrangements (and funeral if need be), make remembrances along the way and during birth, and remember important days for the family for the following two plus years after the child's birth/or loss.

For the first time in my life, I truly feel that I know the "Grace" of God and know that I have experienced it first-hand. I don't know how we would have weathered Joseph's birth and death if we had not stumbled upon that new genetic counselor who just started at our specialist practice. Her tiny knowledge of perinatal hospice care opened so many more avenues of support. Imagine our horror when a year later at 5 months pregnant with our first girl, we were told at an appointment at Children's that our daughter had a rare form of dysplasia and would likely not live past a day. I tell my sponsor from Isaiah's Promise that there is no way our family could have survived that second tragic loss without the support of their program and just as important the Never Alone program at Holy Cross Hospital.

I am coming to the end of my one-page testimony. I humbly ask to share a snapshot in the year of 2016 and 2017 of our family by enclosing the attached documents. The enclosures are communications we shared with our close friends and family; Joseph's, dated October 21, 2016 and Alaina's September 11, 2017.

Thank you for listening to our family's journey of joy and pain and allowing us to share our two precious children with you. Please, do support more information and resources for families such as ours who want to love and support their own children 'as far as they will go'.

Respectfully,

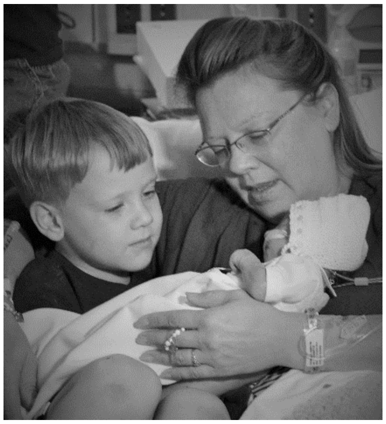
Mrs. Katherine M. Fitzgerald

Mrs. Katherine M. Fitzgerald of Aspen Hill, Maryland

Enclosure

Alaina Elizabeth Fitzgerald Born & Baptized November 30, 2017 Died December 2, 2017 in parents arms

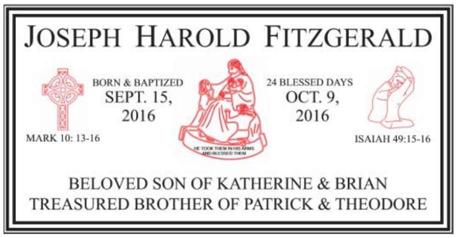
Joseph Harold Fitzgerald, Born & Baptized September 15, 2016 Died October 9, 2016 at home with family



One Week After Joseph.pdf
Uploaded by: Fitzgerald, Katherine
Position: FAV

October 21, 2016

It was one week ago today that I buried my son, Joseph Harold, in the blessed ground of Gate of Heaven cemetery of the Catholic Cemeteries of the Archdiocese of Washington (http://www.ccaw.org/cemeteries_gateheaven.html). We were so lucky to be referred in early May to A.J. Cole (http://www.colefuneral.com/) by our pastor and A. J. made sure Joseph would have a plot in the infant section if and when we needed one. Yes, we literally had to plan our son's funeral before we were even able to plan his birth properly which is how "fun" this pregnancy was for us. As a matter of fact, I remember telling one team of doctors sometime in mid-summer that, "I have already planned my son's funeral I would now like to plan his birth", I said with my baby planner open to A.J.'s brochure and my notes from our meeting with him. Well, we did have an amazing birth as I tell everyone that he is the only one of our three children who came out of me crying and had the highest Apgar scores of all our sons! Go Joseph – you were such a fighter!



JOSEPH HAROLD FITZGERALD

BORN & BAPTIZED
SEPT. 15,
2016

MARK 10: 13-16

HE TOOK THEM IN HIS ARMS
AND BLESSED THEM

24 BLESSED DAYS
OCT. 9,
2016

ISAIAH 49:15-16

BELOVED SON OF KATHERINE & BRIAN
TREASURED BROTHER OF PATRICK & THEODORE

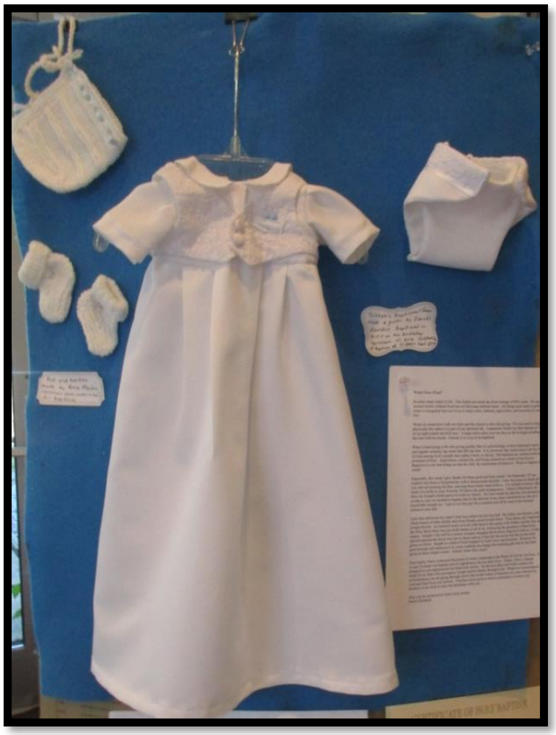
Yesterday, Brian and I were able to sign off on our final design of his bronze flat marker for Joseph's gravesite. It is driving me crazy to not have a marker on his grave. Patrick, my first born, and I went to the cemetery last Saturday and put a beautiful wreath with a slate marker hanging in the middle with Joseph's name and dates of birth and passing. It put me at some ease, but the cemetery only allows flat markers so I was anxious about getting one made ASAP. Again, God has put so many good people in our path along the way since we found out about Joseph's diagnosis at 10 weeks of pregnancy. A. J. referred us to Niv (http://www.frammonument.com/) and he has worked with our family on two different days to get everything that was important to us all to fit on such a small infant marker. We are very happy and trust that during a process that is inevitably slow, Niv will be sure to move it along as quick as he can so Joseph will have his first Christmas present! We are so thankful to all who sent memorials that helped to secure this special marker.

Cards! The cards dear friends and family have sent have been so touching, up lifting, and tear welling. We just got three more today and I do not tire of any – thank you dear friends and family! I look forward to getting the mail and seeing how our precious baby boy is remembered.

Today, my mother and I finished up 54 flannel and polar fleece blankets for the Holy Cross NICU. I picked up Patrick from school and all four of us went to the hospital to deliver the blankets and some newborn and preemie boy baby clothes. It was very cathartic. It was so nice how the nurses took time to dress Joseph (and other babies of course) in actual clothing after his 2nd day in the NICU. They wrapped him and his bassinet pad in a freshly cleaned homemade blanket every day and night. Oh, and the hats – he got a new one to wear every day which is such a nice change from the blue and pink hospital issued baby hat that all babies are given including his big brother Theodore who had to wear his hat for all of his 6 days in the Shady Grove NICU. Mom and I hope to make and give NICU blankets an annual event especially since it will be so near Joseph's birthday. It will be a nice remembrance for both she and I.

Joseph 1 week 9/22/16

Isaiah's Promise continues to offer their support and prayers – Brian and I marvel at how much they have given us and how they have influenced the major epocs of Joseph's life – their volunteers sent Brian and I gifts on Mother's day and Father's day this year when I was pregnant. Gifts that will be ever so important when we celebrate our first Mother and Father's day after our child's birth with no new child to smile upon. It is their volunteers who knitted his first blanket and made his baptimal gown and his burial gown both so perfect and gorgeous. We have nothing but gratitude for their organization (http://www.isaiahspromise.net/



Baptismal gown and diaper cover, Isaiah's Promise

Hat and booties Ann Martin

Burial Gown, Isaiah's Promise

Joseph with Mommy October 6, 2016

Preparing for Alaina.pdf

Uploaded by: Fitzgerald, Katherine

Position: FAV

9/11/17

Twenty six weeks and counting….As many of you know, we have a little girl on the way. We have chosen the name ***Alaina Elizabeth Fitzgerald***. Alaina is Irish for "dear child", and she will certainly be that. Elizabeth is a family name on both sides; on Brian's, Alaina's Grandma's middle name, and on Katherine's, Alaina's Aunt's first name. This name means promised or consecrated to God. We are asking that you all pray for her as much or more than you did for Joseph. Alaina has a condition called Thanatophoric Dysplasia, they believe Type II. We found out at 20 ½ weeks and it was a shock to all. Please do not Google it, as many websites are not kind. Instead, please look at this site, which we feel is the only appropriate website use to learn about the condition: http://www.buttonsandbutterflies.com/2011/04/thanatophoric-dysplasia.html

This condition (TD) is a type of skeletal dysplasia which is not inherited but happens when a specific gene mutates. Her limbs and rib cage will develop at a much slower rate than the rest of her and will be very small. Some bones in the head are also effected which influences brain development. The small ribs are the key, as they will prevent her lungs from developing and making it difficult for her to breathe after birth. We were originally told she would live 1-2 days, but of the cases we know personally, it was only 30-90 min. The prayer we ask from *everyone* is for the miracle that we can take her home so she can pass peacefully with her family in her own house as did Joseph.

The only way I (Brian) can bring myself to conceptualize is like this. Joseph sees what loving brother's Patrick and Theodore are to each other. I believe he wants that same love with him in heaven, and thus he has asked for Alaina to join him up there to play with him and love him like only a sibling can. Katherine feels that God (unfortunately for us) sees us as "strong" loving parents who will give any child what they need in order to get to know their family no matter for how long. Her genetic counselor told her that Joseph told God/Jesus what a great mother she is, and that she and her family are the perfect pick for Alaina.

I know what every one of you is saying, and I agree that this is just not fair and not right. Katherine and I have cried those statements many times since we found out a month ago. Most of the incredible doctors, nurses, and genetic counselors, not to mention the amazing people who have helped us from Isaiah's Promise, (http://www.isaiahspromise.net/ please, feel free to designate them for your amazonsmile donations), have consistently said this is lightning striking twice. If only we were that lucky. The odds of someone being struck by lightning twice in a lifetime is 9 million to 1. The odds of parents having one child with Trisomy 18, and then having a second child with Thanatophoric Dysplasia, are 200 million to 1.

Once again, Katherine has to have a C-section. She will be delivering at Holy Cross Hospital in Silver Spring, MD with the support of the Never Alone program that provides support and special procedures to mothers in these types of severe birth cases. One of the best things they do is allow is your clergy to come into the surgery room for baptism, and this is our plan. Her current birth date is set for November 29, 2017. There is a chance that starting after Halloween her head will be begin to grow too large for a C-section and she may have to be delivered earlier (Prayer # 2 would be for her to make it to 37 ½ weeks).

We take a little solace in the fact that she will be greeted in heaven by her big brother, and will be just as loved with him, as she will be with us. Thanks for all of your love and support the past year, as we could not have made it without you, especially as we approach what would have been Joseph's first birthday this Friday. We will also need you again in the next year, so please keep those good thoughts and prayers coming, as we will need every single one of them. We will do our best to keep everyone updated and informed.

Love,

Brian, Katherine, Patrick, Theodore, our sweet Joseph, and our little Alaina

Harris Testimony SB891.pdf

Uploaded by: Harris, Roisin

Position: FAV

I am writing to respectfully ask you to support this important bill HB1112 / SB891 entitled Public Health - Maternal and Child Mortality - Review and Perinatal Hospice Services.

I believe that this bill would be very beneficial to other families and parents who find themselves being faced with the unfortunate reality of carrying a baby that has been given a fatal prenatal diagnosis. This is the situation I experienced five years ago when I was pregnant with my first daughter, Ember Marie.

At 19 weeks pregnant when I went for my anatomy scan we received the unfortunate news that our daughter had a fatal prenatal diagnosis called bilateral renal agenesis. At this time we were not provided much information other than that I would likely not carry to term as this is incompatible with life. Hoping this information was incorrect I contacted all the local hospitals and each doctor informed us the same thing, they were unable to locate kidneys or get clear images due to lack of amniotic fluid. The lack of amniotic fluid prevents proper lung development which ultimately results in the death of the baby. I was advised by the head of fetal and maternal medicine at one major hospital that I would be risking my ability to have children in the future if I did not "induce early" and that it would be best to just move on and try and get pregnant again. Another major hospital told me that they did not understand why I had not miscarried in the first trimester and that I would lose her any day. We left these hospitals feeling hopeless and discouraged.

After my follow up scan at St. Agnes my regular OBGYN met with us and provided us with a pamphlet for Isaiah's Promise. My OBGYN was familiar with Isaiah's Promise and shared her knowledge of how other mothers had been able to find strength, support and joy throughout their pregnancy thanks to being linked with mothers who had similar experiences. My OBGYN was the only one to provide me with this resource and encourage me to continue my pregnancy.

The mothers I was connected with through Isaiah's Promise shared with me their experiences from receiving the diagnosis to delivering and cherishing their baby. I was encouraged to make the most of every moment pregnant with my daughter and provided with priceless keepsakes such as a handmade baby blanket, mommy and me bracelets, and a necklace that her father still wears every day. Isaiah's Promise was available any time I needed additional support or had questions regarding what I needed to do to prepare for my daughter's birth and death. We were provided with resources on birth plans, local funeral homes, the Trappist Monks (who donated our daughter's casket), and local photographers linked to Now I Lay Me Down to Sleep. Through the support of these amazing mothers we were able to make the most of a heartbreaking situation and chose to celebrate my daughter every chance we could. In spite of what every medical professional had predicted Ember Marie was born alive on May 31st 2016 at 37 weeks and we were able to hold her for all of her short life. Thanks to the recommendations from Isaiah's Promise her father was able to read to her, bathe her and dress her. We were able to have our closest family and friends present as well as the photographer from Now I Lay Me Down to Sleep who was able to capture our first and last moments with Ember Marie. One of the mothers from Isaiah's Promise even came to the hospital and assisted with making hand and footprint molds. I am forever grateful for the support and encouragement I received from Isaiah's Promise that allowed me to treasure and honor my daughter rather than never getting the chance to hold her or meet her. They have continued to support me through the years and most recently with my second pregnancy and birth of Ember Marie's little sister. Without being provided with this resource I never would have known that it was possible to find joy in such a hard situation and I hope that other mothers will be given this same opportunity through Perinatal Hospice Services.

Roisin Harris

8448 Alvin Rd

Pasadena MD 21122

Hartge Perinatal Hospice.pdf

Uploaded by: Hartge, Kelly
Position: FAV

Honorable Members of the Finance Committee,

I'm writing as a mother who has gone through perinatal hospice to urge your support of SB891. A few years ago, I was lucky enough to become pregnant with our daughter, Hope. Unfortunately, at our 20 week anatomy scan, we were told that Hope had a life limiting condition. My husband and I had taken our then 12-year-old son with us to the scan to get to see his brother or sister for the first time. We sent him to the waiting room as we waited for the doctor to come back and tell us what the tech had seen on the ultrasound. The doctor confirmed that our baby girl would not survive long after birth.

At this time, she proceeded to tell us that my health was at risk if I continued the pregnancy and told us that our only option was to abort. She gave us the number of where to call and schedule a D and C. We left the appointment heartbroken and very confused. My husband and I did not get any earlier testing done because we always knew we would continue the pregnancy no matter what, but my husband was so concerned that now my health was possibly at risk. I am a NICU nurse, and I knew that this information was not true but after a doctor had told us that, it was difficult to convince my husband otherwise.

My OB at the time, never reached out to me after receiving the results of the ultrasound so I sought out a new provider. My pastor pointed me in the direction of another doctor, who shared our values. After calling to make an appointment, I received a call less than an hour later from someone with Isaiah's Promise, a support program for families carrying to term after a severe or fatal prenatal diagnosis. They informed me that Gilchrist Hospice had a perinatal department. I reached out to Gilchrist, and from then on had the support from Gilchrist Perinatal Hospice as well as Isaiah's Promise. Gilchrist assigned a nurse to me named Erin. Erin was absolutely wonderful. She would come to my house for meetings to discuss how to come up with a birth plan and what needs we could anticipate prior to and after delivery. She helped set up an interdisciplinary meeting with the hospital staff to go over our birth plan and what we wanted for our child before, during, and after delivery. Erin even set me up with a photographer from Now I Lay Me Down to Sleep, who did a pregnancy shoot with my husband and our son. The photographer also came to the hospital and took pictures on delivery day.

Once Hope was born, Erin came to help with memory making. She brought a kit to do a thumbprint to make a special necklace keepsake. She was there with us every step of the way through pregnancy and delivery. Unfortunately, Hope was born sleeping but even after Hope was born, Gilchrist would reach out to me with information for support groups. I felt very blessed to have the support of perinatal hospice throughout my journey.

As a NICU nurse, I didn't even know that perinatal hospice existed. This truly demonstrates the need for more information to be available to families in need. I think having information regarding perinatal hospice readily available on the health department website and in brochures is vital. So many families are going through this alone and do not know that this support is available to them and for their babies. For these reasons, I urge a favorable report on SB891.

Thank you,

Kelly Hartge
427 Neepier Rd
Catonsville, MD 21228

SB891_SUPPORT_MOD.pdf

Uploaded by: Hessler, Therese

Position: FAV

MARCH
OF DIMES

To: Senator Carozza, Chair and Members of the Senate Finance Committee
From: Venicia Gray, Associate Director, Federal & State Government Affairs
March of Dimes
Date: March 10, 2021
Re: SUPPORT – SB891 – Public Health – Maternal and Child Mortality – Review and Perinatal Hospice Services

Dear Senator Carozza, Chair and Members of the Senate Finance Committee:

The March of Dimes Inc. would like to express support for SB891. This legislation will expand the State's current Maternal Mortality Review Program by offering perinatal hospice programs and resources to families and their babies. Perinatal hospice would offer comprehensive support to a pregnant woman and her family that includes support from the time of diagnosis through the time of birth and death of her baby as well as through the postpartum period.

Neonatal death happens in about 4 in 1,000 babies (less than 1 percent) each year in the United States.[i] Non-Hispanic black women are more likely to have a baby die than women of other races or ethnicities. Premature birth and low birthweight cause about 1 in 4 neonatal deaths (25 percent). Birth defects cause about 1 in 5 neonatal deaths (20 percent).[ii]

The diagnosis of a lethal fetal anomaly poses significant challenges for obstetricians, pediatricians, and clinicians, who often have little experience or training in how to best care for the baby and the grieving parents. According to one study, the most profound effect these pregnancies can leave on families is often a psychological one.[iii]

Perinatal hospice offers the parents of babies with life-limiting conditions the chance to love and cherish their newborns for whatever time they have, from a few minutes to days, weeks or even months. These important programs offer a model of care, an extra layer of support that can easily be incorporated into standard pregnancy and birth care. Ideally, it is a comprehensive and multidisciplinary team approach that can include obstetricians, perinatologists, labor & delivery nurses, neonatologists, NICU staff, clergy, and social workers, as well as genetic counselors, midwives, traditional hospice and palliative care professionals, and others.

A multidisciplinary approach with continuity of care is essential in helping these families understand and adjust to the diagnosis and is also necessary to ensure quality of care through pregnancy, labor and delivery. It is for these reasons March of Dimes urges the Senate Finance Committee for a favorable report on SB891. Thank you.

Sincerely,

Venicia Gray
Associate Director, Federal & State Government Affairs
vgray@marchofdimes.org

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[i] https://www.marchofdimes.org/complications/neonatal-death.aspx
[ii] https://www.marchofdimes.org/complications/neonatal-death.aspx
[iii] https://carryingtoterm.org/wp-content/uploads/2019/12/Hospice_Palliative_Care_Study.pdf

Jenny Mohler Testimony SB891.pdf

Uploaded by: Mohler, Jenny
Position: FAV

Support for SB891, Providing Information on Perinatal Hospice

Honorable Members of the Finance Committee, we write to you as parents who have participated in a Maryland perinatal hospice program to urge your support for SB891.

In the fall of 2012, while 19 weeks pregnant with our second child Joseph Angelo at a routine sonogram, we received the devastating diagnosis of Thanatophoric Dysplasia for our son along with the news that he was not expected to live past birth. Presented with all our options at the time, we chose to continue the pregnancy. We felt that if he was to die, it would not be because of a decision we made and we chose to let nature take its course. We were supported in this decision by an exceptional multidisciplinary team of medical professionals and we participated in Gilchrist Hospice Care as well as Isaiah's Promise, a parent led support group who walked with us on this meaningful and healing journey.

Joseph was born on December 13, 2012 and he lived just an hour after his birth. Because we were prepared and had excellent care, his birthday was a day of not only mourning, but also a day to celebrate the gift of life. We are so thankful to our medical and perinatal hospice team who respected our wishes and allowed us to experience both the joy and pain of saying hello and goodbye to our son, preparing us for death and life at the same time. We have no regrets. We view Joseph's life as a blessing that truly shaped our family and our life today over eight years later.

Since 2013, I (Jenny) have volunteered for Isaiah's Promise, a program that provides parent to parent support to families who choose to carry to term after receiving a life-limiting diagnosis and accompanying them in this difficult yet precious time. Through the years, it saddens me to hear so many stories of other parents who did not receive medical care that respected their wishes, those who were only offered termination, and those who felt alone in their choice and struggled to find resources and a network of support. No parent should feel pressured in a moment of crisis to make an immediate and final decision for their child without all the options presented.

Providing doctors and parents with information on perinatal hospice through brochures and the Health Department website will allow for an improved standard of care in Maryland for these parents. This will increase opportunities for informed decisions and improve parent research following the initial diagnostic appointment when devastated and overwhelmed parents leave the hospital searching for support. For these reasons, we urge a favorable report on SB891.

Thank you for your time, consideration and your service to our community.

Respectfully,

Jenny Mohler, LCSW-C

John Mohler III, DDS

3 Trotters Court

Catonsville, Maryland 21228

For additional information on the Mohler's story and Gilchrist Hospice Care see the attached Baltimore Sun story https://www.baltimoresun.com/news/bs-hs-hospice-perinatal-20130727-story.html

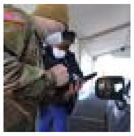
Perinatal hospices help mothers cope with the impending deaths of their babies - Baltimore Sun July 27, 2013

Perinatal hospices help mothers cope with the impe

Uploaded by: Mohler, Jenny

Position: FAV

Why Maryland’s second most populated county has ranked last in vaccinating...



Baltimore Mayor Brandon Scott asks Johnson & Johnson to sell COVID...

COVID vaccines ar
available at
pharmacies,

By BY ANDREA K. WALKER and THE BALTIMORE SUN
JUL 27, 2013 AT 5:01 PM

Jenny Mohler lay on an examining bed holding her pregnant belly at Sinai Hospital in Northwest Baltimore. Sonogram pictures hung from a machine in the right corner of the room. She was nervous, unable to block a feeling of uneasiness as she waited for a specialist to come in and decipher the images.

Just two days earlier, the Catonsville resident had received a call while sitting at her desk at a Catholic Charities health clinic in Baltimore, where she worked as a school counselor. There were developmental concerns about the baby, Dr. Mary Ann Sorra told her. The baby's head was misshapen and its limbs short. Don't worry, Sorra told Mohler, but more tests were needed as soon as possible.

Mohler, who was 19 weeks into her pregnancy, began a frantic Internet search, typing "developmental disorders" and "short limbs" into her office computer. Could it be Down syndrome? Or maybe dwarfism?

As she and husband John, now 33, waited at Sinai that September day last year, he tried to assure her that nothing major was wrong. She wanted to stay positive, but it was difficult.

A perinatologist who deals in high-risk pregnancies came into the room to deliver the diagnosis: Your baby has thanatophoric dysplasia, they remember him saying.

The Mohlers' unborn child was suffering from a rare disorder — whose name meant "death-bearing malformation" in Greek — that would prevent the rib cage from growing, smothering the heart and lungs. The baby would likely be stillborn. Or it would die shortly after birth, unable to breathe on its own.

The baby, whose gender they didn't even know yet, had just been given a death sentence.

Mother, baby at risk

Two months later, across town at Johns Hopkins Hospital, Kimberly Queen lay in a ran from her arm, trying to nourish a boc of shutting down.

Queen's health was deteriorating from hyperemesis gravidarum, a condition that causes severe nausea and vomiting, making it hard for expectant mothers to keep enough nutrients in their bodies. The Elkridge resident had cycled in and out of the hospital her entire pregnancy, and just days before Thanksgiving was admitted to Howard County General Hospital. Her symptoms were so severe that doctors transferred her by ambulance to Hopkins for more specialized care.

A small group of doctors in scrubs entered her room to give Queen and her fiance, Keith Brown, now 34, some news about her fourth child. Brown held her hand while two doctors sat in chairs near the bed. One did most of the talking.

An ultrasound, the doctor said, showed blood and fluid around the brain of the baby Queen had already named Kirsten. The baby's weight was below normal, and she probably wouldn't survive the pregnancy. If she did, her quality of life would not be good. She might not be able to breathe on her own, the doctors said, urging Queen to consider terminating the pregnancy.

Queen, a certified nurse technician at Johns Hopkins Bayview Medical Center, took the news as if she were on the job. She felt the doctors were talking about some other patient, someone other than her. She found herself explaining to her fiance what the doctors were saying, but not fully absorbing the news herself. She said little to them.

But in the middle of the night, her maternal instinct kicked in. She woke up and could only think of one thing: Her baby might die.

Source of comfort

Queen and Mohler discovered themselves in a spot they would never have predicted: grieving instead of celebrating new life and growing families.

Their predicaments would become the most trying they had ever confronted. Doctors encouraged Queen and Mohler to connect with a hospice program to handle the myriad of emotions.

Both women turned to Gilchrist Kids, a division of Towson-based Gilchrist Hospice Care, one of a handful of hospices in the area with a perinatal component. Through the program they were connected with social worker Briana Shirey who became lifeline and source of comfort through their pregnancies.

Queen, now 33, said her doctors focused on the possibility of terminating the pregnancy, and pushed palliative care for the baby to prepare her for death after she was born. But Queen did not want to think about that; she even ignored advice to contact Gilchrist.

"I was feeling my baby moving around in me," she recalled. "I had already seen the sonogram with her features. She had the nose of my son, the mouth of my daughter. In order for me to accept the possibility that my child wasn't going to be here anymore, I had to know I did everything I could to make sure the doctors did what they could to save her."

Still, Queen and her family were having a hard time with all that was happening.

Her fiance Keith had become withdrawn since the diagnosis. Extended family members didn't understand why Queen sometimes chose not to discuss what she was experiencing. They wanted to throw her a baby shower, but Queen didn't want one.

"If [Kirsten] didn't make it, I didn't want to be in a house with a bunch of baby clothes and baby furniture," she said.

And Queen suffered constant anguish thinking about the daughter she might never get to hold alive.

The social worker asked some simple questions: How are you feeling? Is there anything bothering you? For Queen, talking about what was going on brought clarity to her situation and a sense of relief.

"She made it easier to concentrate," Queen said. "She made me realize that whatever happened, I could deal with it."

Shirey visited once a week, assuring Queen that it wasn't selfish to shut out relatives sometimes. Shirey said it was normal to want to be alone, to feel anxious and out of control. She also helped Queen's fiance open up so the couple could support each other.

As they met, Shirey got Queen to understand that she had to accept that her baby might not survive. She coaxed Queen into picking a funeral home — such details would be harder to deal with once the baby was born, Shirey said.

Most importantly, she helped Queen think through a birth plan — a key part of the grief process. Such plans outline how a mother envisions labor and delivery, and list what care the baby should receive after birth.

Queen's plan called for doctors to do "whatever was necessary" to keep Kirsten alive. She also wanted to bathe, dress and hold the baby right away — she knew Kirsten's life might be measured in minutes.

'That is your time'

As the months of pregnancy passed, Shirey also worked with the Mohlers, encouraging them to bond with their child. Talk to the baby, she said. Rub Jenny's belly and interact with him anyway you can, she urged husband John.

"Your time is limited, so during pregnancy, that is your time," Mohler said. "That is your time to love the baby, to bond with the baby and parent while the baby is in the

Jenny, now 32, had no illusions about the chances of their baby's survival — the condition occurs in 1 in 20,000 to 50,000 newborns, and few survive**.** It was the first case Sorra had seen since she began practicing medicine in 1997. The Mohlers had to accept that they wouldn't have long with their baby.

The couple felt unconditional love for their unborn child, and drew strength from their Catholic faith during the pregnancy.

After finding out about their baby's illness, the Mohlers had taken the afternoon off from work and made the 15-minute drive to the Church of the Immaculate Conception in Towson. There they joined others in the adoration chapel, a small building connected to the main church where parishioners go throughout the day to pray.

They sought comfort from God in the modest room with a few rows of simple wood enchairs and stained-glass windows, praying for their unborn child and their family. Then they went to a park near their Catonsville home where they sat quietly, sometimes holding hands, sometimes crying. They worked through a range of emotions — fear, shock, sadness, grief — as they mustered the strength to break the news to their families.

"It was then that we most mourned the loss of our dreams for our son, it was then that it hit me," Jenny Mohler recalls.

Those moments were the hardest the couple, married since 2009 and together five years prior to that, had ever faced together.

The Mohlers hadn't planned on finding out the gender of the baby until it was born. After the diagnosis, they wanted to know. They named him Joseph Angelo Mohler — Angelo because Jenny felt she was carrying an angel in her womb.

They took him to concerts — the Allman Brothers at **Merriweather Post**

"It was hard to explain to her because she was so young," Jenny said. "We just told her that this was her little brother and he would soon be an angel."

'It's not about me'

Creating these memories helps families better prepare for the death of a baby, says Shirey, who lives in Towson. When it actually happens, it does not come as a shock and they are less overwhelmed.

Shirey has been drawn to helping families cope with life's big moments ever since she was an undergraduate studying mental health, social work and psychology. People have always found her easy to talk to and trust, which has helped her in her career.

She has counseled children from abusive families and helped spouses navigate divorces. She thought the hospice job would be a new challenge as advances in prenatal testing put more parents in the position of grieving during pregnancy.

Dealing with death day after day is not an easy job, Shirey acknowledges. She tries not to think about her own family, including her two children. Instead, she focuses on how she can help someone else's family.

But she usually forms bonds with her patients, something that is almost inevitable when people let you into their lives at such a vulnerable time.

"I am not going to say that I don't cry and I don't get sad," she said. "But it's not about me. I can't be there for them if I am emotionally distraught."

Sometimes after a session, she'll sit in her car for a moment and simply take a deep breath.

Precious hour

baby would die in the womb, putting the sonograms throughout the pregnancy to monitor the baby's development.

Within seconds of delivery, Jenny and her husband were greeted by a sound they weren't sure they would ever hear from Joseph. He cried. Their son was alive.

Dr. Sorra felt a sense of relief. She went into the waiting room to deliver the news to the Mohlers' parents.

"Congratulations," she said. "Everything went well. You have a grandson."

John, the father, swaddled Joseph and nuzzled him. He held him up so Jenny could see her son as doctors sutured the incision from her C-section. He then brought him over for Jenny to kiss on the cheek. The parents remember their baby gazing at them almost knowingly.

The Mohlers took their son to another room, where their parents, young Abby, Shirey and other relatives and friends waited. Photos were taken as everyone in the room bonded with the baby. They made molds of his tiny feet and hands.

Their actions stirred the emotions of the medical staff, Sorra said.

"It was extremely moving," Sorra said. "There was so much joy and tragedy at the same time."

Soon, the baby's breaths became further and further apart. He became still, as if he was sleeping. A doctor came in to say Joseph had died.

Joseph lived one precious hour, which the Mohlers say they will remember forever.

"It was very peaceful," Jenny Mohler said. "We didn't even realize he had passed."

Joseph was buried Dec. 22 in a baptism gown made from a recycled wedding dress

The Mohlers say that while they grieved for their son, they had accepted his death. The hospice program helped prepare them for what was to come and create good memories.

"I know most people would expect us to say the most difficult day was the day of his death, but to be honest, it wasn't at all," Jenny Mohler said. "December 13th was an amazingly grace-filled and peaceful day full of love. Because we had good care and we were prepared, the hour we spent with our son was truly one of the most beautiful and meaningful of my life."

'Best sound ever'

As Queen's pregnancy progressed, her baby began to defy the doctor's dire diagnosis. The bleeding in Kirsten's brain stopped and the swelling went down.

She went into labor at 37 weeks on Jan. 13. Doctors at Hopkins were prepared for the worst, stationing equipment nearby to help resuscitate Kirsten if that were needed.

"None of us knew if the baby was going to breathe at birth," recalls Dr. Renee Boss, a neonatologist. "None of us knew if the baby would have a normal heart rate. We were prepared to do whatever we needed to do for the baby if it came to that."

After three days of labor Queen delivered Kirsten, who weighed 5 pounds 9 ounces and had a healthy heartbeat. She looked like her father but had Queen's nose.

"She's breathing," fiance Keith bellowed upon hearing his baby girl's cries. "She's breathing."

Queen felt an overwhelming sense of happiness and relief.

"She came out crying," she recalls. "It was the best sound ever."

was very much alive.

Kirsten stayed for five days in the neonatal intensive care unit for monitoring, but an ultrasound and MRI confirmed that the bleeding in her brain had stopped. The outcome looked promising.

Now 6 months old, Kirsten is home, where her two sisters and brother dote on her. Queen is glad she gave Kirsten the chance to live.

"She beat all odds," said Queen, who also has recovered. "She is showing them wrong every day."

Kirsten is still at risk for developmental problems. The bleeding was in the part of the brain that controls physical development, Queen said. She is one month behind most children her age. But therapy has helped her learn to sit up and react to sounds, such as the shake of a rattle. Therapists are also helping her learn to crawl.

Her parents said no physical disability would stop them from loving their child.

Queen's son Khalil Brown, 5, climbs into his parents' lap as they gaze down at Kirsten.

With a big grin, he said, "Happy family ending."

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Topics: Family, Abusive Behavior, Religion and Belief, Arts and Culture, Culture, Christianity, Roman Catholicism, Howard County General Hospital, Johns Hopkins Bayview Medical Center, Sinai Hospital in Baltimore, Johns Hopkins Hospital

Infant son taught father lessons of love, toleranc

Uploaded by: Sheahan, Molly

Position: FAV

The Washington Post

Local

Infant son taught father lessons of love, tolerance and faith

By Thomas Gravely
June 15, 2012

Editor's note: This eulogy was delivered by the author at the funeral service for his son, Thomas, who passed away in February.

The author is a contributor to The Washington Post's local faith leader network.

Good morning. On behalf of the Gravely and Passyn families, thank you for coming today to show your love and support for our amazing little man Thomas Arthur, Jr., a "Superman" in the truest sense of the word. Of course, the words "amazing" and "super" to describe our Baby Thomas cannot possibly encapsulate his true essence, which profoundly manifested itself during his seven months here on this Earth, and the warmth and joy that he gave to our hearts. As many of you observed during the viewing last evening, our Thomas today is proudly wearing his Superman outfit, equipped with a cape and all, which he wore for Halloween this past year. At the risk of being perceived as silly parents for dressing their son's body in a Superman costume for all eternity, we nevertheless found it a fitting tribute to his life; because if there ever was a soul deserving of the Superman moniker, it was our precious Thomas.

This is Thomas's inspiring story. Nearly a year ago to this day, Elizabeth and I received devastating and heartbreaking news that no expecting parent should ever have to hear. Shortly after Elizabeth's 20 week sonogram, we learned prenatally that our baby Thomas had been diagnosed with an extremely rare chromosomal disorder. In layman's terms, Little Thomas did not have all of the genes that he was supposed to have due to a deletion of a portion of his DNA. This condition affected, in some shape or form, every single living cell in his body. This we knew would result in several brain abnormalities and, as the medical experts would say, other physiological "anomalies." We were told that even if he did survive birth, he could very well have a trifecta of disabilities — blindness, deafness and severe mental retardation. In other words, think of Helen Keller, but without the mental capacity. We were very scared. The doctors gave us a wide range of possible outcomes for Thomas. Although no one was absolutely sure what to expect, at least one doctor informed us that Thomas's chromosomal condition was "not compatible with life," and that he didn't expect the pregnancy to make it full term.

Needless to say, Elizabeth and I were despondent, lost, angry and depressed. We were particularly angry with God at the time, and the thought crossed our minds that perhaps we were somehow being punished by his divine influence. Sure, many family members, friends and support groups reminded us that many parents in our situation go through the similar emotions. Of course they were right, but words of comfort could not take away the pain and anguish that we felt. Thomas's diagnosis notwithstanding, we remained steadfast in our decision to honor the dignity of Thomas's life, and we carried on with the pregnancy. We placed Thomas's fate in God's hands, and we figured that God had a plan for Thomas.

But on July 13, 2011, our Baby Thomas was born kicking, punching, crying and sporting a rather sanguine skin tone (and yes, that was a daddy trait), and much to the astonishment and amazement of the team of doctors on hand in the delivery room, our Baby Thomas was alive! After six days in the NICU, we were finally able to take our Thomas home, which quite honestly, was not something we had prepared for given Thomas's very poor prognosis. What we initially thought of as a curse, turned out to be the greatest blessing from God that we had ever received. Our Baby Thomas was truly a miracle.

Soon after birth, we did learn that Thomas was certainly going to have challenges, but we also knew from the very moment he was born that he demonstrated a strong propensity and desire to live, despite his various syndromic ailments. We vowed that we would do everything within our power as parents to provide a loving environment for Thomas in which he could thrive and flourish. During the course of Thomas's life, he had numerous doctors visits, treatments and hospitalizations. I will not belabor you today with the details of Thomas's many courageous battles during his short time here, because it is ultimately not important, and we would be here, quite literally, all day. What is important is that Thomas fought each obstacle thrown his way with fierce tenacity, and he was triumphant each step of the way. He was a warrior with a strong, yet soft and loving, heart.

Those who had the chance to meet Thomas immediately fell in love with his peaceful demeanor. He was such a good boy, with a pleasant disposition. He had the innate ability to instantly make you feel happy and at peace even if you were in the worst of moods. Thomas did have some vision and hearing impairment, the degree of which we were never really able to determine for sure, but we knew that Thomas could hear our voices, he knew who his parents were, and he was particularly responsive to music, whether it was Coldplay or Beethoven. He knew that he was loved, and he certainly had many happy moments as evidenced by his gleaming smile and soft cooing. We also knew that he was very alert mentally. This gave us hope that Thomas would someday be able to live a fruitful and productive life despite his sensory disabilities. As late as Thursday of last week, and after several promising doctors appointments, we had every reason to be very optimistic about Thomas's progress and his future.

Then this past Friday morning, Baby Thomas suddenly passed away. Elizabeth and I watched in despair as a team of ER doctors and staff desperately tried to resuscitate him, but they were not able to do so. I immediately flashed back to the way Elizabeth and I felt last February when we first learned the news about Thomas's condition...powerless and confused. How could this have happened? Why did it happen? It was as if we were just pawns in some "game" (for lack of a better word) that we didn't understand, and no matter how hard we tried or how much effort we invested, in the end we could not save our Thomas. As parents, we were devastated because Thomas had shown so much progress and development in recent weeks, and we were looking forward to raising Thomas and watching him continue to exceed expectations. Yet, as I stated earlier, God had a plan for Thomas. And for reasons only the Lord knows, Thomas was taken from us.

Since Thomas's passing, I have relied heavily on the words of the serenity prayer to make sense of what transpired last week. Although it is a Christian prayer, I believe its message transcends nearly all faiths and systems of beliefs. I'm paraphrasing, but it goes as follows: "God grant us the serenity to accept the things that we cannot change; the courage to change the things that we can; and the wisdom to know the difference." Granted, easier said than done....but poignant words nonetheless.

Although I do not pretend to have God's omniscient abilities, I have spent considerable time during the past few days pondering the meaning and true purpose of Thomas's life, putting his life into perspective and reflecting on the experiences of the past year with our son and with others...I suppose in a way that only a father can.

What was the meaning of Thomas's life? What purpose did it serve for God to place Thomas on this Earth for nearly 7 months, only to take him away from us much too soon? At first, I didn't have an answer, but right or wrong, I eventually came to my own conclusion after some introspection. And my explanation necessarily begins and ends with the very people sitting within these walls this morning.

You see, Thomas was the epitome of love, in its most perfect and purest form. His life's experiences inspired and united so many people, including many of you, whether you realize it or not. It is, in part, why you are here today in support of his memory. Could it be that Baby Thomas was a messenger? Again, only God knows, but if so, what was Thomas's "message?" Perhaps, he was a reminder to us and our community about the importance of love, and the importance of tolerating imperfection in a society where imperfection has increasingly become intolerable....the importance of valuing all human life.

Thomas's story certainly sparked discourse among us about the importance of love, commitment, and self-sacrifice. I know, because I've had conversations with many of you about what you would do if you were "in our shoes," and if you were faced with the prospect of having a child as special as Thomas. To be able to think about these kinds of issues introspectively, in my opinion, makes one a more compassionate person and makes one appreciate more the fragility of human life and the important role that family and friends play in our lives. This in of itself, certainly gives meaning to Thomas' life.

Some of who communicated to us that you could not possibly understand or comprehend what we were going through, and that you couldn't imagine going through the "burden" of raising a child with Thomas's condition. Yes, last February, Elizabeth and I shared many of these feelings as well...and those feelings are perfectly understandable. But as I stand before you today, and I know Elizabeth feels the same way, I can tell you that having Thomas in our lives was not a burden, not for a moment, and we enjoyed every minute of our time with him, whether it was at home or in the hospital. He truly was a blessing from God. Thomas made me a loving father, a better husband and a better person. For that I am thankful for Thomas, and I am thankful to God for giving him to us, albeit for a brief time.

I was reminded of the importance of family constantly during the past year, where on many occasions I experienced the value of a loving wife, as well as many close and caring family members and friends, including medical professionals, who went beyond the call of duty to assist Baby Thomas.

I was able to witness my beautiful wife, Elizabeth, blossom into motherhood before my very eyes. I am thankful to God for having her in my life, and she was certainly "Supermom" to Little Thomas in every sense of the word. The experiences we shared together with Thomas during this past year reaffirmed why I fell in love with her in the first place, and our love is even stronger now thanks to Thomas. Could that also have been part of God's plan? I would like to think so. Thank you Elizabeth, for your enduring love and support throughout all of this. I couldn't have made it this far without you. I love you.

Elizabeth and I would also like to thank our many family members, friends and work colleagues for their love, support and invaluable advice during this past year. I cannot possibly name everyone, but you certainly know who you are.

Thomas’s true miracle is not that he exceeded doctors’ expectations, but that he united our families and friends through his love and our love for him. Ultimately, I believe that this was Thomas’s purpose on this Earth.

Although there are genes that determine how tall we are, what color eyes and hair we will have, or whether or not we will even be able to see or hear, I do know that there is no gene for love, and there is certainly no gene for the human spirit. Thomas had both in droves and a power that transcended his bodily form. He is a true Superman.

And as promised, I will conclude my vision of Thomas’s legacy with where I began, with all of you with us today. All that I ask is that you remember Thomas and his story. How he touched and inspired so many lives and taught so many the importance of love, tolerance and affection. For those of you who have young children, hug them just a little bit tighter before they go to bed tonight. Please make them understand that your love for them is unconditional and that you will always fight for them with all of your ability. You, as parents, are their number one advocates. That is what Thomas taught us.

And finally, I must say goodbye to my Thomas. I was honored to be your father. You made me so very proud, and I will never forget what you have taught me. Thank you my son. I will always love and cherish you, and I look forward to the day when we can hopefully meet again in the kingdom of Heaven. God bless you.

Thomas Gravely lives in Rockville, Md.

6 Comments

Maryland Catholic Conference_FAV_SB891.pdf

Uploaded by: Sheahan, Molly

Position: FAV

MARYLAND CATHOLIC CONFERENCE

ARCHDIOCESE OF BALTIMORE ✝ ARCHDIOCESE OF WASHINGTON ✝ DIOCESE OF WILMINGTON

March 10, 2021

Senate Bill 891
Public Health - Maternal and Child Mortality - Review and Perinatal Hospice Services
Senate Finance Committee

Position: SUPPORT

The Maryland Catholic Conference represents the public policy interests of the three Roman Catholic (arch)dioceses serving Maryland: the Archdiocese of Baltimore, the Archdiocese of Washington, and the Diocese of Wilmington, which together encompass over one million Marylanders.

Senate Bill 891 would ensure the State Department of Health maintains a list of perinatal hospice programs on its website and creates a printable brochure for physicians and nurse practitioners to share with families who want the information.

Perinatal hospice and palliative care is specialized care provided to families when their baby is given a life-limiting diagnosis in utero and may have just days or hours to live after birth. From the time of diagnosis through delivery, the multidisciplinary perinatal hospice team provides physical, emotional and spiritual support. They empower families to process the diagnosis, find moments of meaning making, welcome their baby and say goodbye. This care is widely accepted by medical professionals, including by the American College of Obstetricians, Society for Maternal-Fetal Medicine and the American Academy of Pediatrics.[1]

Maryland parents deserve to know all of their options, presented in a sensitive manner, when given a life-limiting diagnosis in utero. Yet few Maryland families receive information about perinatal hospice or are treated insensitively and feel abandoned and without support at this difficult time. Providing this information respects the autonomy, choice, and decision making of parents.

Pope Francis, in an address to perinatal hospice professionals, called perinatal comfort care "an approach to care that humanizes medicine," where "parents are helped to process their mourning and to comprehend it."[2] Perinatal hospice emphasizes dignity, comfort, and a peaceful experience for the whole family. Families are encouraged to collect remembrances like photos and handprints and given the gift of time with their baby. Ultimately, research shows 98% of parents who used perinatal hospice said they had no regrets and cherished the experience they had to love, hold and meet their baby for the duration of their life, no matter how brief.[3]

Families deserve to have this information. It is for these reasons that the Maryland Catholic Conference respectfully urges a favorable report for **SB 891**. Thank you for your consideration.

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[1] "Perinatal Palliative Care," Obstetrics & Gynecology September 2019, Vol. 134,3

[2] Pope Francis, Address to Yes to Life Conference, 25 May 2019

[3] Wool, et.al. "'I Would Do It All Over Again': Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis" Journal of Clinical Ethics, Fall 2018 Vol. 29,3

Heather Silver LCSW SB891 Testimony.pdf

Uploaded by: Silver, Heather

Position: FAV

Silver Leaf Consulting

March 7, 2021

Thank you to the Chair and members of the committee. My name is Heather Silver and I am a perinatal specialist. I work with families who suffer the loss of a pregnancy or infant, as well as provide perinatal hospice services. Imagine going to a sonogram appointment excited to get your first set of pictures, find out the sex, or see and hear your baby's heartbeat for the first time, only to hear those heart-breaking words; Something is wrong with your baby.

Perinatal hospice is a philosophy of family-centered care that addresses the intentions of families who choose to continue a pregnancy with a life-limiting condition. The goals are to anticipate, prevent, and relieve suffering, to preserve dignity, and to promote quality of life for baby and family, while honoring the parent's wishes for their baby's care regardless of length of life.

Perinatal Hospice focuses on creating a relationship with parents and guiding them in decision making and caregiving. After birth, the care also focuses on the comfort and well-being of the baby, with interventions to support quality of life for both baby and family. Parents must balance the dual experience of preserving hope with preparation for birth and eventual death—or of death and then the birth. It is creating a safe space with parents and understanding their goals. These goals shift and change over time. They go from "I hope the diagnosis is wrong", to "I don't want my baby to suffer", to "I want a peaceful death.".

I have been involved in bereavement care since 2001 and it is heart-breaking that in 20 years we have barely advanced the movement of perinatal hospice. These services are necessary. They are special. They prove over and over again that they impact families mental health and well-being in a positive way.

Brochures highlighting these resources should be given to physicians because they are present when the diagnosis happens. These families choose their provider, therefore this would be a trusted source. This also helps a family have a place to start instead of going home and googling their diagnosis which can be packed with misinformation. Only 10% of information is retained after receiving traumatic news…leaving the office with resources in hand is vital. Families turn to the internet for information and the Health Department should provide this information so it can be the trusted source for these families.

I travel around and give presentations to OBGYN office, hospitals and clinics and its astounding how many doctors and other providers are not aware of perinatal hospice, not aware of what services are offered, and not even aware there are local resources for their patients.

Parents that utilize perinatal hospice are able to process their grief, they are able to have an advocate for their wishes, and they are able to understand their options. Let me give you an example of two sets of families I am currently working with.

The first family was sent to me by their doctor at the point of diagnosis, at about 20 weeks gestation. I was able to help the family process the baby's life-limiting diagnosis of a major heart defect.

We discussed all of their options, I worked with them to help with communication between one another, as well as managed their expectations and hopes. We planned for the birth and eventual death of their baby. We recorded their baby's heartbeat, we provided them with extra sonogram photos, and planned maternity pictures. We also planned a special baby shower where we did a belly painting and a belly cast to honor the family and friend's relationship with this baby. We organized a photographer for the birth, and did 3-D hand and foot molds after the baby was born. We worked with the baby's siblings, explaining death to them in a way that was age appropriate and did legacy building that honored their relationship with their unborn sibling, as well as helped the parents anticipate their grief needs. All of the burial and funeral plans were completed during their sessions. This allowed them to fully focus on the limited time they had with their baby after birth. They found great comfort in the baptism they had performed by their priest who came to the hospital when it was time, and being able to make meaning of the loss from pre-planning for the mom to donate her breast-milk helped her feel as though her baby continued to make a positive impact.

The second family came to one of my support groups approximately 3 months after their loss. Their baby also had a severe heart defect which resulted in a stillbirth at 38 weeks gestation. The hospital staff was compassionate. They took pictures with their own phones and were given a memory box with a special bracelet and special blanket. After birth while they were spending time with their baby they had to meet with hospital staff to discuss disposition options and make all of their plans. Would they like cremation or burial? What funeral home would they like to use? Did they want someone to bring a special outfit? Because it is up to various hospital staff that already have so much responsibility to have these conversations, things get lost. There is limited time to make these choices and most parents aren't able to process what each outcome would be. The mom was never told her milk would come in. Many mom's don't realize this is a part of loss and can be extremely traumatic when this happens. By the time they are able to access support they are extremely uncomfortable and it takes much more time and effort to stop this from happening.

At the support group this family was able to listen to the other family who had perinatal hospice involved from the start. This resulted in another round of grief. They now knew what they had missed and this turned into anger and resentment. This was pointed at their OB providers, their hospital, and the staff. It was too late. What could have changed their entire experience? What could have helped them plan and prepare for their baby's arrival and maximize their time with their special little one? A simple brochure with a list of resources.

This is a bill to empower parents to make decisions for their baby because they deserve a choice. They deserve information. They deserve your vote which honors their relationship with their baby and gives them control over something when they are swimming in a river of the unknown.

For these reasons I urge a favorable report on Senate Bill 891. Thank you for your time and attention.

Sincerely,

Heather J. Silver, LCSW-C, CPLC

Perinatal Hospice SB891 Support - Mary Ann Sorra M

Uploaded by: Sorra MD, Mary Ann
Position: FAV

natural fertility care
OBSTETRICS AND GYNECOLOGY
Mary Ann Sorra, M.D., FACOG

March 7, 2021

Dear Senate Finance Committee,

I am a board certified Obstetrician/Gynecologist born, raised and educated in Maryland, and practicing in the Baltimore area since 2001. I am writing to request a favorable report on Senate Bill 891 which advocates for perinatal hospice services.

One of the hardest parts of my job is to tell a pregnant woman that her unborn baby is likely to die in utero or soon after birth because of a grave illness. It's the most dreaded news a parent can receive. But these parents are amazing. With the support of perinatal hospice they learn to pour a lifetime of love into months, cherish every day that their baby lives, yet still prepare themselves for inevitable, devastating loss.

As an obstetrician, I provide the medical care to keep my patients physically healthy during the pregnancy and birth. Perinatal hospice provides the emotional, psychological and spiritual care. I have managed patients before and after perinatal hospice was available, and I cannot overstate the value of their services.

You might imagine that the days these babies are born are simply dreaded days of despair and mourning. But they are not. Because of perinatal hospice, the day of delivery is still filled with the joy of welcoming a new baby into the world who is unconditionally loved by his parents, no matter how brief the life may last.

All Marylanders and expectant parents should know that perinatal hospice is available to help through the difficult journey of perinatal loss.

Sincerely,

Mary Ann Sorra, M.D., FACOG
1001 Pine Heights Ave. Ste, 203
Baltimore, MD 21229

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Phone 410 644-1908 • Fax 410 525-3569 • naturalfertilitycaremd.com

sb 891 amendment.pdf

Uploaded by: Carozza, Senator Mary Beth
Position: FWA

SB0891/853329/1

AMENDMENTS
PREPARED
BY THE
DEPT. OF LEGISLATIVE
SERVICES

26 FEB 21
17:12:04

BY: Senator Carozza
(To be offered in the Finance Committee)

AMENDMENTS TO SENATE BILL 891
(First Reading File Bill)

AMENDMENT NO. 1

On page 1, in line 2, strike "**Review and**"; and strike beginning with "authorizing" in line 4 down through "issues;" in line 9.

On pages 1 and 2, strike in their entirety the lines beginning with line 25 on page 1 through line 5 on page 2, inclusive.

AMENDMENT NO. 2

On pages 2 through 5, strike in their entirety the lines beginning with line 15 on page 2 through line 15 on page 5, inclusive.

SB 891 Senator Carozza Written Testimony.pdf

Uploaded by: Carozza, Senator Mary Beth
Position: FWA

MARY BETH CAROZZA
Legislative District 38
Somerset, Wicomico,
and Worcester Counties

Education, Health, and Environmental Affairs
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THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

March 10, 2021
The Senate Finance Committee

Senate Bill 891 Public Health - Maternal and Child Mortality - Review and Perinatal Hospice Services

Statement of Support by Bill Sponsor Senator Mary Beth Carozza

Thank you, Chair Kelley, Vice Chair Feldman, and members of the Senate Finance Committee for this opportunity to present and request your support on Senate Bill 891- Public Health - Maternal and Child Mortality - Review and Perinatal Hospice Services.

The bill requires the Maryland Department of Health to publish a list of perinatal hospice services in Maryland on its website and requires the Department to provide an information sheet of these services in English and Spanish. It also would authorize physicians and nurse practitioners to inform patients of services available and provide the information sheet produced by the Department under this bill. Lastly, it would authorize that perinatal hospice programs may request to be on the Department's list. Senate Bill 891 would help ensure new parents can receive information about perinatal hospice support when facing a life-limiting diagnosis in utero and the likely loss of their child just hours or days after birth.

Perinatal hospice services may include support throughout the pregnancy, delivery, and post-partum period; guidance regarding medical decisions; assistance with making memories, pictures, or keepsakes; a personalized birth plan; pain relief for the baby if necessary; memorial or funeral service guidance; and coordinating discharge from the hospital to home or hospice program.

There are over 300 perinatal hospice programs in the United States, nine programs in the State of Maryland, and currently no perinatal hospice programs serving my constituents on the Eastern Shore. Perinatal hospice is widely accepted by medical professionals and generally covered by maternity and newborn care insurance. It emphasizes dignity, comfort and a peaceful experience for the whole family.

Seven states have passed similar legislation including the model legislation our bill is based on that passed in Nebraska in 2017, known as the Compassion and Care for Medically Challenging Pregnancies Act. It requires their health departments to provide perinatal hospice resources and make it easily accessible. Echoing other states' progress on access and transparency to these services, Senate Bill 891 would advance awareness of perinatal hospice in Maryland and greatly benefit families during a difficult time.

As an active member of the Maryland General Assembly’s Women’s Caucus, I recently had the pleasure of hearing from Dr. Dina El-Metwally who is a member of the Maryland Perinatal Clinical Advisory Committee at the Maryland Department of Health (MDH) for the taskforce of renewal of the Perinatal System Standards (2019-2024). I was alarmed that her research showed that there was a 120 percent increase of infant Mortality in Somerset County in my District since the beginning of the COVID-19 pandemic.

The urgency to pass Senate Bill 891 is heightened given that the infant mortality rate has continued to increase and that families have lacked knowledge and resources, with minimal options. Eighty-eight (88) infants have died due to conditions that would likely have merited perinatal hospice in 2018. This does not include the number of families who received a prenatal diagnosis and chose termination or those who received a prenatal diagnosis and the infant was miscarried or stillborn. Senate Bill 891 would benefit several hundred Maryland families every year to access the available perinatal hospice resources.

I am pleased to report that there is broad support for the bill including several hospices in Maryland including Coastal Hospice in Salisbury, MD, the Hospice of Frederick County, the Compass Regional Hospice and Talbot Hospice that serves Talbot, Caroline, Queen Anne’s and Kent Counties. Senate Bill 891 is also supported by the Maryland Catholic Conference and parents across the state.

My panel today will explain more of the direct benefits of perinatal hospice services and how it affects the lives of so many families. The panel includes Mary Peroutka who is the founder of the first perinatal hospice in Maryland, Heather Silver, perinatal hospice support staff and bereavement counselor at Silver Leaf Counseling in Anne Arundel County, and Meg Aeschlimann who is a parent that utilized perinatal hospice services.

I respectfully ask my colleagues on the Senate Finance Committee for a favorable report of Senate Bill 891.

Thank you for your kind consideration.

2021 PPM SB 891 Senate Side.pdf

Uploaded by: Elliott, Robyn
Position: UNF

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Planned Parenthood of Maryland

Committee:	**Senate Finance Committee**
Bill Number:	**Senate Bill 891**
Title:	**Public Health – Maternal and Child Mortality Review and Perinatal Hospice Program**
Hearing Date:	**March 10, 2021**
Position:	**Oppose**

Planned Parenthood of Maryland (PPM) opposes *Senate Bill 891 – Public Health – Maternal and Child Mortality Review and Perinatal Hospital Program*. PPM supports ensuring pregnant individuals have comprehensive and accurate information about all pregnancy options. For individuals carrying a fetus with a lethal abnormality, it is important and appropriate for health care providers to provide information about perinatal hospice. We also believe individuals should receive information about other clinical options, including abortion. We oppose this legislation because it is not inclusive of all clinical options, and it mandates health care providers relay specific information to patients about perinatal hospice programs. We do not believe it is appropriate to mandate speech for health care providers in statute. Health care providers should base their recommendations to patients on clinical evidence rather than statutory mandates. We ask for an unfavorable report.

SB0891 MD NARAL OPPOSE.pdf

Uploaded by: Philip, Diana

Position: UNF

NARAL
PRO-CHOICE MARYLAND

SB0891 - Public Health – Maternal and Child Mortality – Review and Perinatal Hospice Services

Presented to the Hon. Delores Kelley and Members of the Senate Finance Committee
March 10, 2021 1:00 p.m.

POSITION: OPPOSE

NARAL Pro-Choice Maryland urges the Senate Finance Committee to issue **an unfavorable report on SB0891 - SB0891 - Public Health – Maternal and Child Mortality – Review and Perinatal Hospice Services** sponsored by Senator Mary Beth Carozza.

Our organization is an advocate for reproductive health, rights, and justice. As part of our efforts to protect reproductive freedom for all Marylanders, we work to ensure every individual has the right to decide if, when, and how to form their families, and to parent in good health, in safety, and with dignity. We honor pregnancy in all its complexity, advocate for those who wish to bear healthy children, and fight against reproductive coercion. We respect the expertise of healthcare and social work professionals in providing comprehensive perinatal and postpartum care, as well as counseling which includes palliative hospice services for fatal fetal anomalies. We understand the need for maintaining patient-provider trust in regard to reproductive and pediatric care, including the involvement of patients in care-continuation and decision-making.

Fatal fetal abnormalities can occur at any point during the pregnancy, most often resulting in genetic malformations such as trisomy 13, a condition resulting in severe physical and cognitive anomalies that usually results in infant death during the first week postpartum, and anencephaly, in which a child is born without all or some parts of their brain.[1] These anomalies are almost always discovered during pregnancy; as a result, providers begin discussing options with patients when the diagnosis is made, putting together a team of social workers, pediatricians, OBGYNs, and palliative care specialists to provide care based on the decisions of pregnant patients and their families.

This bill is unnecessarily reiterating a referral system or palliative care program available in most hospitals and allowing the state to dictate the type of resources being offered in physicians' offices. By recommending that healthcare services offer information on programs that are not vetted by the physicians themselves, it puts women and patients at risk for further complications and breaks an already delicate patient-provider trust network. Physicians give medical advice based on the needs and wishes of their patients, and further providing pregnant people who do not wish to consider pediatric palliative care with these materials could cause further psychological distress and trauma. This bill also fails to consider the already established and

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[1] Heuser CC, Eller AG, Byrne JL Survey of physicians' approach to severe fetal anomalies *Journal of Medical Ethics* 2012; **38:**391-395.

vetted hospice programs that exist in hospitals. There are over 212 pediatric palliative care programs nationwide, with over 50% of all programs located in a hospital or fetal diagnostic center.[2] Having palliative care support systems available from the moment of diagnosis is essential for ensuring the best outcome for the pregnant person while still respecting their pregnancy wishes.

Finally, this bill uses problematic language in how it identifies a fetus. The language refers to all fetuses as "unborn child", assuming that all mothers have the same viewpoint about their pregnancy. When identifying and providing support for pregnancies resulting in fetal abnormalities, it's essential to identify and use the patient's preferred terminology (such as baby, pregnancy, or fetus) and to continue using the correct identifiers so as to not cause further distress or discomfort to patients. The goals and objectives of the patient must align with the palliative care team, and as a result, continuous communication about terminology and intended pregnancy outcome is essential. We also suspect that the authors of this bill seek to pass legislation toward the goal of establishing a fetus as having personhood, when puts all pregnant people in harm's way of losing their bodily autonomy and the right to determine the outcome of a pregnancy.

We fear that by asking healthcare providers to provide options on pediatric palliative care programs outside of hospital settings, and not vetted by the providers themselves, that patients will be coerced into options that they are not comfortable with. The state does not have a right to dictate what is said in doctors visit and should not counsel women without the input of their own providers on options regarding continuation of care.

For these reasons, NARAL Pro-Choice Maryland **urges an unfavorable committee report on SB0891.** Thank you for your time and consideration.

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[2] Marc-Aurele, K., Hull, A., Jones, M., Pretorius,D. A fetal diagnostic center's referral rate for perinatal palliative care. *Annals of Palliative Medicine*. 2017;7(2). https://apm.amegroups.com/article/view/14687.

SB891_Boss_LOI (004).pdf

Uploaded by: Boss, Renee
Position: INFO

SB891

Letter of Information

TO: The Honorable Delores Kelly

Chair, Senate Finance Committee

FROM: Renee D. Boss, M.D., M.H.S.

3212 Juneau Place

Baltimore, MD 21214

DATE: March 10, 2021

My name is Dr. Renee Boss and I am an Associate Professor in the Department of Pediatrics at the Johns Hopkins School of Medicine and Director of Pediatric Palliative Care at the Johns Hopkins Children's Center. I am an international expert in serious fetal and neonatal illnesses, with a focus on providing young parents and families with the services needed to support grief and bereavement. I am concerned that Senate Bill 891 will mislead families and potentially limit their access to available resources in our community. I submit this testimony as a physician and concerned resident of Maryland. I am not representing the view or position of the Johns Hopkins University or School of Medicine.

SB891 addresses the case where a pregnant woman receives the diagnosis of a fetal condition likely to result in the infant death. SB891 advocates that the Department of Health create website information and a printed information sheet about "perinatal hospice services." SB891 states that inclusion of a perinatal program in the website/ information sheet will occur via request by the perinatal program, with no requirement for or system to evaluate the program's licensing or credentialling.

Palliative care is highly specialized medical care provided by a trained team of clinicians. This team includes medical personnel, counselors and spiritual care providers who treat children with serious illness via a combination of medical and emotional supports. Pediatric palliative care teams are trained to support the families of these children, often helping them make difficult medical decisions.

Hospice is a discreet element of palliative care that focuses on the final months of life. Hospices are licensed, credentialed inpatient and outpatient facilities certified to care for dying patients. Hospices are required to provide 24/7 access to medicines and interventions delivered by medical personnel. Hospices also have highly trained teams of psychological and spiritual professionals to support the entire family at the end of life and during bereavement. These specialized family supports can begin before birth, in the case of a prenatal diagnosis.

While SB891 use the term "hospice," there is no evidence that the programs to be included on the website/ information sheet will meet the professional or legal standards of hospice care as delivered by trained medical professionals. Parents may therefore be misinformed about the quality of those programs, with potential impact on the medical decisions they make for their child.

I am very concerned that SB891 would hinder parent and child access to high quality, licensed palliative care and hospice services.

SB0891_INFO_HPCNM_Perinatal Hospice Services.pdf

Uploaded by: Kauffman, Danna

Position: INFO

Hospice & Palliative Care Network
OF MARYLAND

March 10, 2021

Dear Senator Kelley and Members of the Senate Finance Committee:

The Hospice and Palliative Care Network of Maryland appreciates the opportunity to provide this Letter of Information on **Senate Bill 891: Public Health – Maternal and Child Mortality – Review and Perinatal Hospice Services.** Please note that this letter is premised on our understanding that the sponsor will be introducing amendments for the Committee's consideration to remove provisions in the bill related to the State Child Fatality Review Team and the Maternal Mortality Review Program. With those amendments, Senate Bill 891 seeks to provide information to a pregnant woman and her family on perinatal hospice services when a physician or nurse practitioner has diagnosed an unborn child as having a lethal fetal anomaly.

While we fully support the intent of Senate Bill 891, we are concerned that this bill may be premature given that this is an unreimbursed service under the commercial market and Medicaid is not required under licensure standards. Without insurance coverage, these services are currently provided solely through philanthropic support and many hospices are unable to subsidize the expenses associated with such a program.

Perinatal hospice is a comprehensive multidisciplinary framework designed to support families who are carrying unborn babies with life threatening diagnoses. The support roles that are offered through perinatal hospice include access to the following services and professionals - Bereavement Specialists, Child Life Specialists, Volunteers, Chaplaincy, Social Work, Certified Perinatal Loss Care Nurses and Hospice Physicians. Important to families during this difficult time are tasks such as pre-planning funeral arrangements for their baby, telling siblings in the home that their baby sister or brother is going to die, helping to process grief in a pregnant mother, supporting a father who shares his own unique grief, preparing birth plans that communicate a family's wishes in the delivery room and supporting the hospital staff. Perinatal hospice teams, through research and experience, are trained and excel at addressing these challenges. Most families facing the challenges of potentially losing their newborn express that it is a very isolating time with extremely limited resources. Hospital based medical teams who are caring for them also express that they struggle finding community supports for this very unfortunate niche population. Clearly, there is a tremendous need for perinatal hospice care.

The Hospice and Palliative Care Network of Maryland is willing to work with the Committee to determine necessary steps needed to ensure that perinatal hospice care is a covered benefit. We thank you for the opportunity to provide you with this information.

For more information:

Peggy Funk
Executive Director
The Hospice and Palliative Care Network of Maryland
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