Abigail is amiracle and gift from God. Her birth is an occasion for rejoicing. Please refer to her as Abigail and share our joy {and sorrow} with us.

Our intent is to have Abigail guide us in determining the type of care she will be provided immediately after delivery. **As a result of honoring Abigail’s strength to fight, her care after delivery may result in full intervention OR providing comfort care with minimal intervention. Due to the possibility of full intervention, we request to have the NICU team present during delivery to assist with assessments and prepared to respond if full intervention is chosen. Jamie and Brian will determine the type of care provided to Abigail after her delivery based on the information provided from initial assessments.** If Abigail is unable to sustain lifesaving measures, and her condition begins to deteriorate, we wish to be the ones holding and caring for her at the time of her death. As a result, we ask that all possible procedures be done in our presence or delayed until her condition is assessed to see if she is stable.

We truly appreciate your help and support, and ask that you understand if we seem indecisive at times. We also appreciate and find great comfort in your expressions of grief, be it through tears or humor, so please do not hesitate to cry or be sad in front of us, if that is how you feel.

**JAMIE’S CARE/GENERAL INFORMATION**

* It is very important that NOBODY enter the room without knowing our situation and if possible, for us to receive a room somewhat secluded from other delivering parents. If Abigail is born still or passes away shortly after delivery, Jamie requests to be moved to a different floor of the hospital for the remainder of the stay (if this is possible). Note: The hospital kept us on the delivery floor and moved us to a larger room to allow for visitors and photography. The staff explained that if they moved me to a different floor, they would not have the post-partum care available. We recommend including the request to remain in the birthing suite, if possible.
* We would like to have our stay during Abigail’s delivery and Jamie’s recovery to remain private. We would like to be informed of all guests that are requesting to visit before they are allowed in our room.
* Any drugs used should have minimal side effects while still providing pain relief; giving it in the smallest dose that will be effective. Jamie wants and needs to be alert and mobile as soon as possible after delivery. Her preference is to avoid an epidural with other means of pain management (however, remains open to the idea of epidural if needed). Note: After many conversations with doctors, it was determined that an epidural would be the best option for Abigail in terms of reducing transferred stress.
* Preferred method of delivery is to be vaginally, unless Jamie’s health is at risk and it is deemed necessary for a c-section. This is Jamie’s 3rd pregnancy, with two previous uncomplicated vaginal deliveries.
* We would love photos and video taken in the delivery room if possible, by any nurse or staff that is available whether Abigail is born still or alive. We understand this may be uncomfortable for some staff given the situation, but we are aware our time with Abigail may be brief.
* In the event of a stillbirth or loss, if the hospital has any contacts for receiving an Angel Gown, we would be grateful to receive one. Note: Prior conversations with the hospital social worker allowed us to receive an angel gown shortly after we checked into the hospital.
* At our request, please assist us in contacting Now I Lay Me Down to Sleep and notify them of our wish to have photos taken if a photographer is available. We would like to have a chance for Abigail’s siblings to join us at the hospital for photos and we can coordinate with our family to have them join us.

 Note: You can find an area coordinator by visiting their website <https://volunteers.nowilaymedowntosleep.org/find-photographers>

* + [Insert name] - Area Coordinator

Mobile Phone: XXX-XXX-XXXX

Home Phone: XXX-XXX-XXXX

Other Phone: XXX-XXX-XXXX

[Email address]

* At our request, please assist us in contacting Pastor [insert name] from [insert name] Church. Pastor [insert name] will be baptizing Abigail whether she is born still or alive, Pastor [insert name] can be reached at XXX-XXX-XXXX. If our pastor is unavailable, we may request the hospital provide us with a Chaplain to provide services.
* If a death certificate needs to be filled out, our daughter’s legal name will be [insert full name].
* Should Abigail be born still or pass away after delivery, [insert name] Funeral Home has stated they are in no hurry for Abigail’s body and we can keep her as long as we need. If we choose to do so, we may transport Abigail’s body to the funeral home after signing the appropriate legal documentation. Phone XXX-XXX-XXXX.

**ABIGAIL’S FULL INTERVENTION CARE**

* If possible, Brian would like to cut the umbilical cord whether Abigail is born alive or still.
* If Abigail is born alive, please perform standard suctioning, rubbing, vigorous drying to aid in Abigail’s respiratory and cardiac efforts, and required assessments. Please do not perform any unnecessary testing/procedures that would cause pain or discomfort (shots, testing, drops). Following testing/assessment:
	+ If Abigail can breathe on her own and is stable, please allow Jamie and Brian time to hold her *briefly* before taking her to NICU.
	+ If she cannot breathe on her own, please fully intervene medically and we will hold her after interventions.
* We expect Abigail to be provided full medical interventions.
	+ In the event she has difficulty breathing, please provide CPAP or Vapotherm (or similar). If neither work, please ventilate and/or intubate her.
	+ In the event that an intervention is likely to cause an earlier demise, please consult with Jamie and Brian prior to initiating.
* PLEASE RESUSCITATE ABIGAIL AS NEEDED.
* If not alive and unable to be resuscitated at delivery following all possible medical interventions, we want Abigail to stay with us for as long as we feel necessary. We ask that you give us privacy to grieve, without abandoning us. Please encourage us to do whatever feels right.
* Morphine-based pain medication or any pain medication that may exacerbate apnea MAY NOT be used without prior discussion and consent.
* We would like to consult with specialists regarding Abigail’s medical conditions, including:
	+ **Neurology:** Based on prenatal ultrasound findings, Abigail has a splayed cerebellum and a widened CSP. We would like to understand the severity of these findings by having any combination of ultrasound, MRI, and EEG to provide Abigail the appropriate care.
	+ **Cardiac:** Abigail has been diagnosed with a large VSD. Please provide heart monitoring and an echo and cardiac assessment to confirm the prenatal cardiac findings. Should Abigail live, we will discuss the pursuit of heart surgery and other medical interventions as soon as possible if she is stable.
	+ **ENT:** Most Trisomy 18 babies have either central and/or obstructive apnea and we request a sleep and swallow study at the earliest available time to determine the cause of any apnea Abigail might experience and any other issues.
	+ **Urology:** We request to have an ultrasound completed for Abigail’s kidney(s). Based on prenatal findings, Abigail has left kidney renal agenesis. Her right kidney has UTD A2-3.

**ABIGAIL’S PALLIATIVE CARE**

* If Abigail has a heartbeat at the start of labor, we do not wish for constant fetal monitoring as we are aware labor/delivery may cause distress to Abigail. Abigail’s heart rate can be periodically checked throughout labor where it seems warranted.
* Brian would like to cut the umbilical cord whether Abigail is born alive or still.
* If Abigail is born alive, please perform standard suctioning, rubbing, and vigorous drying to aid in Abigail’s respiratory and cardiac efforts. Positive pressure, bag and mask ventilation may be used immediately after delivery for up to one minute to initiate breathing only, not to maintain breathing. No artificial airway afterward.
* We ask that Abigail be quickly handed to Jamie or Brian after her birth whether she is alive or born still.
* If warranted, Abigail will be supplied extra oxygen only if it aids in her comfort.
* Medication to promote comfort and ease pain may be administered. Morphine-based pain medication or any pain medication that may exacerbate apnea MAY NOT be used without prior discussion and consent.
* No extra-ordinary means should be taken to prolong her life.
* No Vitamin K and ointments are to be administered.
* We desire no warming tables, etc. Rather, use warm blankets with skin-to-skin contact against Jamie or Brian’s chest.
* Please delay all procedures (weigh, measure, footprints) until both parents have held Abigail and if possible, these procedures should be done while the parents are present or holding her. If there are any procedures that absolutely need to be done outside the room, Jamie or Brian will go with Abigail.
* If Abigail is born alive, conscious, and is interested, Jamie would like to breastfeed her. If Abigail shows difficulty with nursing or swallowing, we still desire for Abigail to receive some kind of nutrition. Our first preference is breast milk – Jamie would like to express breast milk if Abigail is unable to nurse. We are open to suggestions of other feeding methods which may be easier and more effective for our daughter.
* Since we don’t know how long Abigail will live, we want to spend as much time with her as possible. If Abigail’s condition begins to deteriorate, we wish to be the ones holding and caring for her at the time of her death.
* Whether Abigail is born alive or still, Jamie and Brian would like to give Abigail her first bath and clothe her at a time they feel comfortable with doing so.
* Please help us to make as many memories as possible by giving us any mementos including bassinet card, hats, hospital ID bracelet, SEVERAL hand and footprints on individual pages of paper, handprints on a baseball (provided), and hand and foot impressions (we have kits to use). We would also like several locks of her hair, if she has any (baggie and drawstring provided). Note: We had a special book for Abigail that we read to her and had her footprints on the last page. We requested the nursing staff fill out a bassinet card, as one was never actually made. The hospital actually had their own plaster molding kits and we both had a mold made of Abigail holding our finger.
* If Abigail is stable, and Jamie is released, we desire to take her home ASAP on comfort care OR we would like to be able to remain in the hospital for as long as necessary in order to prevent frequent visits.
* If Abigail is born still or passes away during our stay, we want Abigail to stay with us for as long as we feel necessary. We ask that you give us privacy to grieve, without abandoning us. Please encourage us to do whatever feels right.

**ABIGAIL’S TRIBE**

Our wish is to have a private labor and delivery without family members present. We will notify family after Abigail’s delivery when we are open to having visits. If family members request to visit, Jamie and Brian will coordinate individual visit times with family members. Note: It is important to communicate with your social worker or hospital staff if you wish to have family members present during labor and delivery. If space allows, they will reserve an area for your family to gather.

* [Insert name], age X – Sister/Brother

**Our wish is to refrain from using the term “sick” as we do not want [insert name(s)] to correlate being sick to Abigail’s diagnosis or condition. Due to the age of Abigail’s sisters, we are not explaining the diagnosis of Trisomy 18 or death. If Abigail is born still or passes during our stay, our wish is to say that Abigail is sleeping. Note: We were blessed to have a very thoughtful doctor discuss this request with us. The doctor explained that some children become fearful of sleeping as they associate this with death (this is something we never thought of). The doctor offered the suggestion of using language such as “Abigail has something wrong with her cells, she has Trisomy 18”. Although we still chose not to explain death at that time, we took the doctor’s advice on alternate terminology and explained that Abigail had something wrong with her cells; she had Trisomy 18. We informed the girls that when we come home, Abigail would not be with us because she was going to heaven, up in the sky. As the girls get older and they have their own questions, we will be open and honest with them.**

* [Insert name & insert name] – relation to baby (relation to you)
* [Insert name & insert name] – relation to baby (relation to you)
	+ [Insert name] – Cousin
* [Insert name] – relation to baby (relation to you)
	+ [Insert name] – Cousin