Patient name: _____ DOB: _____ Date: _____

At our hospital, your baby and family are our top priorities. Our goal is to provide the very best care, while honoring your preferences for your birth and post birth experience. The Neonatal and Perinatal Palliative Care (NPPC) team has designed this advance care plan to meet the unique needs of families whose baby is diagnosed before or after birth with a high chance of extreme prematurity, life-limiting condition (high risk of death), premature labor, prolonged rupture of membranes and/or has a chronically complex medical condition. This plan will assist you in not having to share the same details, over and over again, to a multitude of caregivers.

The NPPC team understands that making decisions about your infant's advance care plan, under these difficult circumstances, can be overwhelming and challenging. The purpose behind this advance care planning is to serve as a guide for your wishes/desires during labor, delivery, postpartum, and neonatal care for your infant. It will assist us to ensure that your hopes, goals, and values are integrated into the plan of care, therefore allowing you to form precious memories with your infant. We ask that you complete each of the sections of this plan to the best of your ability. We are available if you should have questions or concerns related to this form. Please note the completion of this form does not mean this a finalized and "set in stone" plan for your experience. If at any time, you decide that revisions need to be made feel free to contact the NPPC team so that we can assist in making sure that your desires/wishes are met to the best of our abilities.

General Background Information

Mother's full name _____

Primary support's name _____

Baby's full name _____

Is there a certain time that your baby needs to be named? _____

Is there a person who gives and/or first speaks the baby's name? ☐ Yes ☐ No

If yes, who? _____

Our baby's condition or diagnosis is: _____

We have a complete understanding of this condition: ☐ Yes ☐ No ☐ Desire additional information

What we expect about our baby's health issues: _____

Our due date is: _____

Name(s) and age(s) of sibling(s): _____

Our address: _____

If primary support's address is different: _____

Our phone number(s): _____

Mother's email: _____ Primary support's email: _____

The best mode of communication is: ☐ Mail ☐ Email ☐ Phone

Preferred language: ☐ English ☐ Spanish ☐ Other _____

Our family's greatest strengths: _____

Our family's greatest fears: _____

Obstetrical Care

Prenatal testing you have had done:

- ☐ Ultrasound
- ☐ Genetic testing
- ☐ Amniocentesis
- ☐ Other _____

Genetic counseling was provided by _____ (name of counselor)

Our OB/Gyn provider is _____

He/She is with OB/Gyn Practice _____

We plan to deliver at _____ (hospital)

Labor and Delivery Care

Please circle your choice for the questions below.

We have been informed that **there is / is not** a high risk for a stillbirth.

We **want / do not want** our baby's heartbeat to be monitored during labor.

If our baby's heartbeat is monitored during labor, we prefer **continuous / periodic monitoring.**

If there is a loss of a heartbeat prior to delivery, we **do / do not** wish to be informed.

If out baby is a stillborn, we request:

- ☐ Time alone
- ☐ Other _____

Intervention on Behalf of Fetus

We have discussed the issue of a C-section with:

Provider's name _____ Affiliation _____

On date _____

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

We are aware that there are greater risks to the mother associated with a C-section delivery when compared to a vaginal delivery. We know that a C-section may be necessary if an unexpected obstetrical issue arises that puts the mother's or fetus's health in danger. We know that a C-section is not a guarantee of a live birth.

We **want / do not want** a C-section for problems seen during fetal monitoring (Please circle one).

We would like _____ (Name) to cut the cord after delivery, if possible.

We request that our baby be handed to his/her mother or primary support immediately after delivery, if circumstances allow: ☐ Yes ☐ No

We would love to have the following individuals present **before** and **at the time** of birth: (Please circle one)

_____

_____

For our baby's comfort, please postpone the following routine procedures only if death is imminent: (Please check all that apply)

- ☐ Vitamin K injection (helps with blood clotting)
- ☐ Hepatitis B vaccine (protects against the Hepatitis B virus)
- ☐ Antibiotic eye ointment (prevents eye infections)
- ☐ Weight and length

We request that, if possible, routine and necessary procedures be performed with our baby in our arms:

☐ Yes ☐ No

We would like to have our baby in the room with us for all routine care: ☐ Yes ☐ No

Additional Testing

For the purpose of chromosome studies or other special testing to help determine a cause for our baby's condition, please collect:

- ☐ Cord blood
- ☐ Chromosome/microarray
- ☐ Tissue collection/biopsy

We are most concerned about:

_____

_____

_____

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

Support after Delivery for Mother

- ☐ I would like to receive postpartum care on the mother baby unit (around other postpartum families and babies)
- ☐ I would like to receive postpartum care on a quiet Women's Center unit (no babies)

Support after Delivery for our Baby if Death is Imminent

- ☐ We do NOT want our baby to go to the Neonatal Intensive Care Unit (NICU)
- ☐ We do want our baby to go to the NICU
- ☐ I would like my primary support to stay with me
- ☐ I would like my primary support to go with our baby
- ☐ As soon as possible, we would like an update called to us regarding our baby's condition

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

Managing Our Baby's Medical Needs

THIS PAGE IS ESSENTIAL TO FILL OUT

We have been informed of the natural history of our baby's diagnosis and the prognosis associated with this life-limiting condition.

Resuscitation Guidelines

If our baby is born alive: (Please check one)

☐ We desire ALL **life prolonging, aggressive medical interventions** to possibly prolong our baby's life even if they may cause discomfort, pain and suffering

- ○ **FULL RESUSCITATION**
  - Suctioning, intubation, CPAP, oxygen delivery, surfactant delivery, chest compressions, resuscitation medications, emergent IV line placement, insertion of needle aspirations and chest tubes into body to withdraw air or fluid, placement of ventilator with continuous reassessment and open communication with family

☐ Desire to TRIAL Resuscitation to possibly prolong our baby's life

- ○ **TRIAL RESUSCITATION**
  - Suctioning, intubation with assessment of heart rate, possible chest compressions, resuscitation medications, emergent IV line placement with continuous reassessment and open communication with family

☐ We want **COMFORT CARE** only for our baby. We do NOT wish to extend his/her life through heroic measures, such as intubation, ventilation or resuscitation. We want our baby to receive medication to promote comfort, but not to extend life. Comfort Care includes: 1) warmth, swaddling, holding, 2) oral/nasal suctioning to clear secretions, 3) medication as needed to relieve discomfort, pain, and suffering, 4) feeding as decided by us and 5) family time and bonding.

- ○ **DO NOT RESUSCITATE**
- ○ **Initiate Comfort Care**

Please note, sometimes despite all resuscitation efforts attempted, the medical team may **NOT** be able to prolong or save your baby's life and they will come to you to initiate Comfort Care.

Any Special Considerations:

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

Feeding Our Baby

We would like to attempt to breastfeed as able _____

Bottle feed formula or breastmilk by bottle _____

Use oral sucrose _____

Feed by feeding tube _____

IV fluids _____

Use a pacifier _____

We would like to speak to a Lactation Consultant _____

We would like information regarding breastmilk cessation/stopping _____

We would like information regarding possibly donating breastmilk to Milk Bank Program _____

Spiritual Support

Are there special spiritual considerations that we should know in order to provide support to you?

What is your religious/spiritual affiliation?

Our faith traditions include:

We request that a ceremony (blessing, naming ceremony, baptism, etc.) be performed in accordance with our religious beliefs

The following Faith Community representative will be present with us:

Please list name(s) of individual(s), affiliation, and phone number(s)

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

Would you prefer if your caregivers called your Faith Community representative?

We wish our Faith Community Representative to be present at the following times: (Please check all applicable)

- ☐ Before
- ☐ During
- ☐ After birth
- ☐ At time of death
- ☐ After death

We would prefer assistance from the hospital chaplain: _____

Family Time

Please check all that apply.

- ☐ We would like our designated family members present during the delivery, if possible.
  - ○ We would like to designate _____ to give family and friends updates.
- ☐ We would like family/friends to be able to join us in the room after delivery to spend time with our baby and us.
- ☐ We would like privacy (except for caregivers)
- ☐ Are there certain family members, community members, or spiritual leaders who need to be present or notified?

_____

- ☐ We would like to hold our baby as soon as possible and as much as possible.

_____

- ☐ We would like to perform Skin to Skin holding as soon as possible.

_____

- ☐ We would like to bathe our baby.
- ☐ We would like the nurse to bathe our baby.
  - ○ Are there any practices around cleansing of the body?

_____

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

- ○ Where, when, and by whom is the bathing done?

_____

_____

☐ We would like to dress our baby.

- ○ We have brought our baby's clothes and blankets.

_____

- ○ We will want these clothing items back.

_____

- ○ We want our baby left in the clothing.

_____

- ○ We would like to use an Angel Gown from the hospital for our baby (free of charge).

_____

☐ We would like our other children present before, during, and after the birth.

Please list names and ages:

☐ If our baby is stillborn or when our baby passes away, we would like him/her to stay with us in our room until we are discharged: ☐ Yes ☐ No

☐ We **do / do not** wish our baby to go to the Morgue (Please circle choice).

☐ We **do / do not** wish our baby to be picked up in our room by the funeral home (Please circle choice).

☐ We will be taking the baby's body with us upon discharge. ☐ Yes ☐ No (Paperwork required)

End of Life Care

Plans for our baby, should his/her death occur prior to hospital discharge, will include:

Autopsy: ☐ Yes ☐ No Organ donation, if applicably: ☐ Yes ☐ No

☐ We have made funeral and/or cremation arrangements with (name of the funeral home and phone)

_____

☐ We will need to see the funeral/cremation directory

_____

☐ Other end of life care requests for our baby

_____

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

Special Keepsakes/Memory Making

If possible, we would like to have the following keepsakes:

☐ Little Light Program (free of charge) photographer

- Do you want a caregiver to contact the photographer for you? _____
- Would you like to contact the photographer for pictures before and after birth?

_____

☐ Photos	☐ Tape measure	☐ Canvases
☐ Footprints	☐ Crib card	☐ Hat
☐ Plaster foot molds	☐ Blanket	☐ Lock of hair
☐ ID band	☐ Clothing	☐ Stuffed animals

☐ Other _____

Plans for Discharge

How your baby responds to labor and birth will be unique. Depending on the diagnosis and its effects, there is the potential your baby could live for a few minutes, hours, days, or months. In the event your baby is discharged from the hospital, NPPC will assist you with identifying community based hospice care support services.

We would like our baby to be home when he/she dies if at all possible. _____

Do you have a preference for home hospice? _____

We would prefer to go to inpatient hospice home if available (instead of being at our home)

_____

Do you have a Pediatrician? Please provide a name, practice and phone number:

_____

Do you need assistance finding a Pediatrician for after hospital care? _____

Do you need information on the Ronald McDonald House? _____

Additional Requests for our Advance Care Plan

Please use this space to list additional requests for your advance care plan:

_____

_____

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label

This advance care plan was completed after discussion with the following medical providers:

(Please print name, title, phone number, date)

_____

_____

Signatures of Parent(s): This advance care plan serves as a **guideline** for our wishes/desires for the delivery and care of our baby. We understand our plan **MAY NOT** be able to be followed in its entirety due to the unique needs of our baby, or to extenuating circumstances beyond our control. Our signatures allow for appropriate disclosure of this medical information to other participating health care providers/caregivers that will be involved in our care.

Mother's signature _____ Date/Time _____

Primary support's signature _____ Date/Time _____

Our hospital is committed to providing the very best care for you and your baby, while supporting your preferences for your experience. Once your plan is complete, please send of copy of this advance care plan to:

Novant Health at Forsyth Medical Center

3333 Silas Creek Parkway – 3rd Floor North Tower Neonatology Administration

Attn: Patricia Vandergrift - Palliative Care Coordinator

Winston-Salem, NC 27103

In addition, please give a copy to your OB provider and keep a completed advance care plan with you when you are admitted to the hospital. It will help us ensure your wishes are integrated into your plan of care. Please notify your nurse upon admission, to the hospital, that this advance care plan is in existence and that you have met with the NPPC team.

If you have questions or concerns regarding this advance care plan, please call 336-718-3173 for assistance.

If limited English proficient or hearing impaired, offer interpreter at no additional cost:

☐ Interpreter Accepted _____ ☐ Interpreter Refused

(Name/Number of Person/Services Chosen/Used)

Patient Name:_____

DOB:_____

(or use patient label)

Name / MR # / Label