

A stylized graphic on the left side of the slide. It features a large, dark blue silhouette of a person's head and shoulders, facing right. Inside the blue shape, there is a smaller, orange silhouette of a child, also facing right. The child is positioned as if being held or embraced by the larger figure.

TTAC

Perinatal and Early Childhood
Mental Health Network

Training and Technical Assistance Center

Introduction to Pregnancy and Infant Loss (PAIL)

Nneka Hall, Presenter

Who We Are

The New York City Perinatal and Early Childhood Mental Health Training and Technical Assistance Center (TTAC), is funded by the NYC Department of Health and Mental Hygiene (DOHMH).

TTAC is a partnership between the New York Center for Child Development (NYCCD) and the McSilver Institute for Poverty Policy and Research.

- **New York Center for Child Development** has been a major provider of early childhood mental health services in New York with expertise in informing policy and supporting the field of Early Childhood Mental Health through training and direct practice
- **NYU McSilver Institute for Poverty Policy and Research** houses the Community and Managed Care Technical Assistance Centers (CTAC & MCTAC), and the Center for Workforce Excellence (CWE). These TA centers offer clinic, business, and system transformation supports statewide to all behavioral healthcare providers across NYS.

TTAC is tasked with building capacity and competencies of mental health professionals and early childhood professionals in family serving systems to identify and address the social-emotional needs of young children and their families.



Visit the TTAC Website

A Variety of Features:

- View upcoming and archived content, trainings, and resources on the **Trainings page**.
 - Access videos, slides, and presenter information
- Contact the TTAC team by clicking on **Ask TTAC** and filling out our **Contact Us form**
- And more!

Have questions or need assistance? Please contact us at **ttac.info@nyu.edu** and we'll be happy to assist you

Explore all the provider resources at ttacny.org



About Trainings Resources Clinical Services

**NYC Perinatal & Early
Childhood Mental
Health Provider
Resources**

Learn More



TTAC
Perinatal and Early Childhood
Mental Health Network
Training and Technical Assistance Center



McSILVER INSTITUTE
FOR POVERTY POLICY AND RESEARCH
NEW YORK UNIVERSITY



NNEKA HALL

- Mother of 4
- BS Public Health
- MS Mental Health and Wellness, Candidate
- Quietly United in Loss Together, Founder
- Mother IS Supreme, Inc. Founder
- International Bereavement Specialist
- Maternal / Fetal Health Advocate
- Commissioner, Ellen Story Postpartum Depression Commission 2019 - 2024
- Commissioner, Racial Inequities in Maternal Health Commission, 2021 - 2022
- 2016 Nominated Change Maker, US of Women Summit
- Founding Member of Boston Community Action Network, 2016 - 2021
- 2020 State of the Union, guest of Congresswoman Ayanna Pressley
- 2021 Ambassador, Count the Kicks
- 2022 GenUnity Health Equity Cohort Member
- 2024 GenUnity Andrew Dreyfus Incubator



*"I have been blessed
for in you, I found love."* 



Annaya Marie
August 27th, 2010



TRIGGER WARNING!!!

Reminder: This is a bereavement webinar!!!

We will be talking about sensitive information surrounding grief, death and dying. Some of the material will be raw. It may trigger emotions you were not aware of. We will not know when you are triggered if you do not voice it.



FAIR Advocacy

EMOTIONAL RESPONSES TO TRIGGERS

- Sadness
 - Tears
 - Trembling
- Fear
- Anger
- Frustration
- Anxiety
- The need to flee



PAILAdvocate

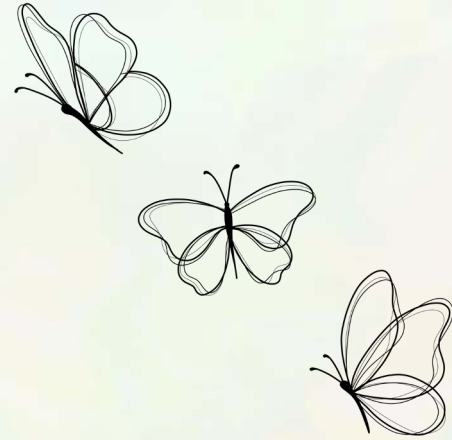
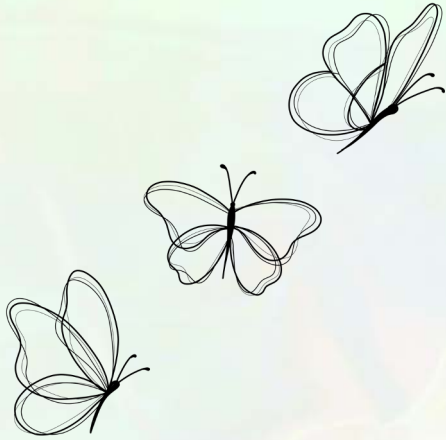
WHAT IS PREGNANCY AND INFANT LOSS?



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PREGNANCY LOSS

ABORTION
MISCARRIAGE
STILLBIRTH
FATAL DIAGNOSIS
PAILAdvocate



PREGNANCY LOSS

ABORTION

The ending of a pregnancy after, accompanied by, resulting in or closely followed by the death of an embryo, fetus, baby.

MISCARRIAGE

Spontaneous loss of a pregnancy before the 20th week, 24th week or 27th week (depending on where they're located) usually occurring before the 12th week.

STILLBIRTH

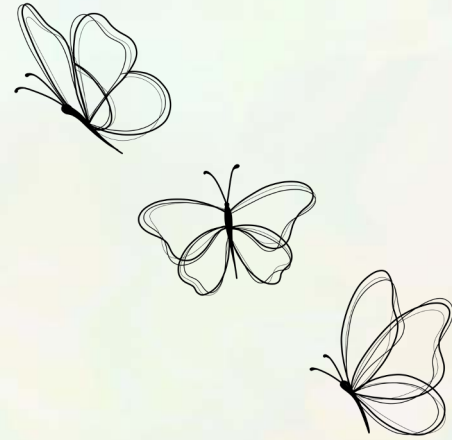
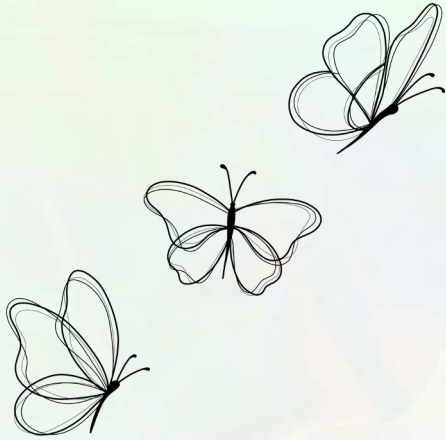
A fetal death that occurs after 20, 24, 27 or 28 weeks of pregnancy. (Please find out your state/country's guidelines regarding pregnancy loss.)

PREGNANCY LOSS

FATAL DIAGNOSIS

A pregnancy in which a baby may die prior to or shortly after birth due to an irreversible illness.

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INFANT DEATH

PREMATURITY

**SUDDEN INFANT DEATH SYNDROME
(SIDS)**

**SUDDEN UNEXPECTED INFANT DEATH SYNDROME
(SUIDS)**

SHAKEN BABY SYNDROME

MISCELLANEOUS CAUSES



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INFANT DEATH

PREMATURITY

A birth that takes place three weeks or more before the baby's due date.

SUDDEN INFANT DEATH SYNDROME (SIDS)

The unexplained death of an infant, usually during sleep, before the first birthday.

SUDDEN UNEXPECTED INFANT DEATH SYNDROME (SUIDS)

The unexpected unexplained death of an infant before the child's first birthday (not sleep related).

INFANT DEATH

SHAKEN BABY SYNDROME

Injury to a baby caused by being shaken violently and repeatedly. Shaking can cause swelling of the brain, internal bleeding, detached retinas leading to blindness, mental retardation, and/or death.



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MISCELLANEOUS CAUSES

- Chronic illnesses
- Accidents
- Abuse
- Miscellaneous illnesses

TERMS TO KNOW

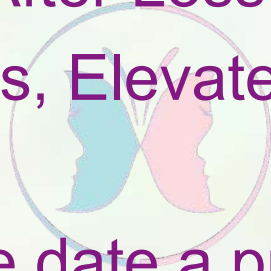
- PAIL - Pregnancy and Infant Loss
- Sunshine - A child born (alive) before a pregnancy loss.
- Rainbow - A baby born/conceived after a pregnancy loss or death of a child.
- Pot of Gold - A baby born/conceived after a rainbow (alive).
- BLM - Baby Loss Mom
- SIL - Sister, Sistah, Sistar In Loss



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TERMS TO KNOW

- TFMR - Termination for Medical Reasons
- PAL - Pregnancy After Loss
- HELLP - Hemolysis, Elevated Liver enzymes and Low Platelets
- Angelversary - The date a pregnancy / baby was lost (died)
- Heaven Born - Miscarried or stillborn, deceased
- Earth Born - Born ALIVE
- Spontaneous abortion - Death of a fetus



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ABORTION & COMPLEX GRIEF



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An abortion is the ending of a pregnancy after, accompanied by, resulting in or closely followed by the death of an embryo, fetus, baby.

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SURGICAL ABORTION METHODS

- Dilation and Evacuation (D&E)
- Manual Vacuum Aspiration(MVA)
- Induction
- Dilation and Curettage (D&C)
- SofTouch



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CHEMICAL ABORTION METHODS

- RU-486 (Mifepristone)
- Methotrexate and Misoprostol
- “Morning After” Pill



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COMPLEX GRIEF

- **Guilt**
- **Shame**
- **Relief**
- **Anger**
- **Sadness**



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SUPPORTS

- Hold hand
- Listen (follow your client's lead)
- Keep your opinions to yourself
- Offer a healing ritual (memorial, plant a flower or tree, give back to the community)
- List of therapists
- Offer a list of support resources
- Womb steaming (2 to 3 weeks after procedure)
- Raspberry Leaf Teas, Tinctures, and/or pills for uterine healing.
- Do nothing



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**Healing begins when we name the pain
and create space for it to be witnessed.**



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MISCARRIAGE

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A miscarriage is the spontaneous loss of a pregnancy before the 20th week, 24th week or 27th week (depending on where they're located) usually occurring before the 12th week.



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MISCARRIAGE CAUSES

- **Chromosomal abnormality**
- **Advanced maternal age**
- **Hormonal problems**
- **Infections**
- **Maternal health condition**
- **Lifestyle (smoking, drug use, malnutrition, exposure to toxic substances)**
- **Maternal trauma**
- **Improper implantation of egg in the uterine lining**



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MISCARRIAGE SIGNS (Physical)



- **A decrease in hcg levels**
- **Bright Red Spotting**
- **Mild to severe backache/cramping**
- **Sudden decrease in pregnancy signs and symptoms**

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MISCARRIAGE TYPES

- **Threatened**
- **Inevitable or Incomplete**
- **Complete**
- **Missed Miscarriage**
- **Recurrent Miscarriage**
- **Blighted Ovum (Also called an an embryonic pregnancy.)**
- **Ectopic Pregnancy**



FAITH Advocate

MISCARRIAGE TREATMENTS

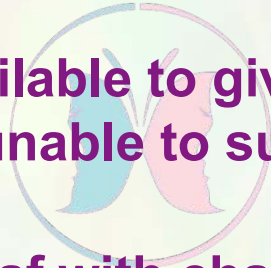
- Natural (unassisted) release of the pregnancy
- Medication (Cytotec)
- Surgical (D&C, MVA)
- Herbal



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SUPPORTS

- Have a miscarriage kit available to give your client
- Phone support if you are unable to support in person
- A fresh pot of bone broth
- A fresh pot of raspberry leaf with chamomile and cramp-bark
- Have a grief resource list (miscarriage specific) to give your client



BAT Ad-opts

SUPPORTS



- **Healing circle/memorial for the baby (if family desires)**
- **Ask your client if they would like you to attend her follow up appointment with client**
- **Crystal healing (Rose quartz, aquamarine, sodalite, rainbow moonstone, etc)**
- **Closing of the Bones Ceremony**
- **Continue to add**

WHAT'S IN A MISCARRIAGE KIT?

- Pain Relief
- Cheesecloth (to line the toilet to prevent baby falling into the commode)
- Gauze
- Chucks (Thick disposable sheets to protect bed/couch/favorite chair)
- Overnight herbal pads
- Cotton balls
- Rice Sock (to go into the microwave)



DAII Advocates

WHAT'S IN A MISCARRIAGE KIT?



- **Small Tupperware/wooden box/decorative box (for baby's remains)**
- **Raspberry Leaf Tea**
- **Gatorade / Coconut water**
- **Journal**
- **Aromatherapy**
- **Adult Coloring Book**



A miscarriage is a sacred loss. It deserves to be named, honored, and held with care. Every parent deserves the right to grieve, to remember, and to heal in their own way, in their own time.

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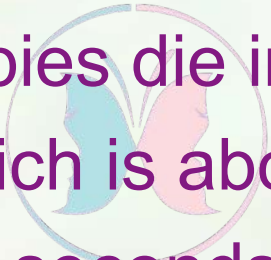
STILLBIRTH

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A stillbirth is a fetal death that occurs after 20, 24, 27 or 28 weeks of pregnancy. (Please find out your state/country's guidelines regarding pregnancy loss).



“About 2 million babies die in stillbirth (worldwide)
each year, which is about one every 16
seconds.”

The logo for PAIL Advocate features a circular emblem containing two stylized human figures, one in blue and one in pink, facing each other. Below the emblem, the text "PAIL Advocate" is displayed in a serif font, with "PAIL" in blue and "Advocate" in pink.

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World Health Organization

UNITED STATES



5.3 per 1000 births

PAIL Advocate
1 in 160

CDC

STILLBIRTH CAUSES

- **Chromosomal abnormality**
- **Fetal Growth Restriction**
- **Placenta and Cord Problems**
- **Premature birth**
- **Advanced maternal age**
- **Hormonal problems**
- **Infections**



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STILLBIRTH CAUSES

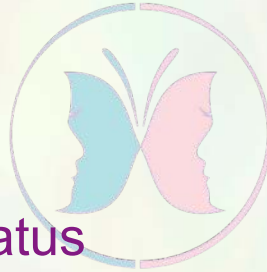
- **Maternal health condition**
- **Lifestyle (smoking, drug use, malnutrition, exposure to toxic substances)**
- **Maternal trauma**
- **Medical Mishap**



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CDC SAYS YOU'RE AT RISK IF

- are black
- are 35 years of age or older
- are of low socioeconomic status
- smoke cigarettes during pregnancy
- have certain medical conditions, such as high blood pressure, diabetes and obesity
- pregnant with multiples
- have had a previous pregnancy loss



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BIRTH OPTIONS



- **C – Section is only an option during extreme cases**
- **Vaginal delivery using drugs to induce**
- **Vaginal delivery waiting for natural labor to begin**

POSSIBLE PREVENTIONS

- Kick counting beginning 26 weeks (for multiples or high risk pregnancies) or week 28 (uneventful pregnancies)
- Self Advocacy
- Advocate for babies
- Womb Wellness
- Measure umbilical cord



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EMOTIONAL AND PSYCHOLOGICAL IMPACT

- **Profound guilt, isolation, anger and isolation**
- **Trauma responses**
- **Disenfranchised grief**
 - **Loss can be minimized**
 - **Loss can be invalidated**



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SUPPORTS

- Remember that regardless of the outcome, a baby is being born
- Hold hand
- Open Ears, Closed Mouth
- Listen (follow client's lead)
- Keep your opinions to yourself
- Treat the family the same way you would any laboring family
- Take down the clock in the birth room
- Slow things down
- Stay in the moment
- Breathe
- Take a moment if you need one



PAIN Advocate

SUPPORTS

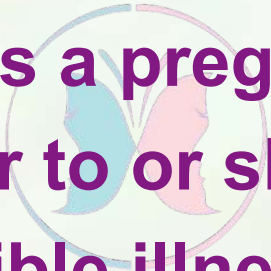
- Ask the family if they would like to see, hold, unswaddle their baby
- Would family like to do skin to skin?
- Find out if mom and/or dad, grandma, siblings, auntie, etc. would like to wash, dress the baby (with your assistance)
- Take as many pictures as possible (these are the only memories the family will have)
- Advocate for the parents/family to spend as much time with the baby as possible.
- Always refer to baby using the baby's name or as your baby
- Something simple, can be magical
- Set up resources BEFORE discharge
- Meal train so family won't have to worry about the basics



FATAL DIAGNOSIS

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A fatal diagnosis is a pregnancy in which a baby may die prior to or shortly after birth due to an irreversible illness.

The logo features a circular emblem with a blue butterfly on the left and a pink butterfly on the right, both facing each other. Below the emblem, the text "PAIL Advocate" is written in a serif font, with "PAIL" in blue and "Advocate" in pink.
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CONDITIONS RELATED TO FATAL DIAGNOSIS

- Anencephaly
- Arthrogryposis Multiplex Congenita
- Balanced Translocation
- Cri-du-chat
- Dandy-Walker Syndrome
- Hydrocephalus
- Congenital Cystic Adenomatoid Malformation
- Congenital Diaphragmatic Hernia
- Congenital Heart Defects
- Molar Pregnancy
- Potter Syndrome
- Triploidy
- Trisomy 13



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CONDITIONS RELATED TO FATAL DIAGNOSIS

- **Chromosome 15 Trisomy**
- **Trisomy 18**
- **Trisomy 22**
- **Turner Syndrome**
- **Twin to Twin Transfusion Syndrome**



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Remember... Downs Syndrome was once considered a Fatal Diagnosis

OPTIONS



- **Abortion / Release the pregnancy**
- **Carry to term**
- **Perinatal Hospice (after live delivery)**
- **Take baby / babies home**
- **Relinquish custody**

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EMOTIONAL



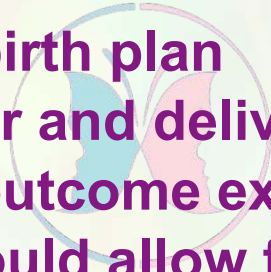
- **Grief is layered and anticipatory**
- **Ambiguous loss is experienced**
- **Guilt, Anger, Numbness and Deep Sorrow**
- **Decisions are deeply personal and are often shaped by faith, culture and values.**

SUPPORTS

- **Help the family enjoy every moment of their pregnancy.**
- **Help the family create a bucket list of things to do in order to cherish every moment.**
- **Refer the family to a support group for people who are experiencing or have experienced a fatal diagnosis.**
- **Support their decision whether it is to abort or to carry to term without judgment**

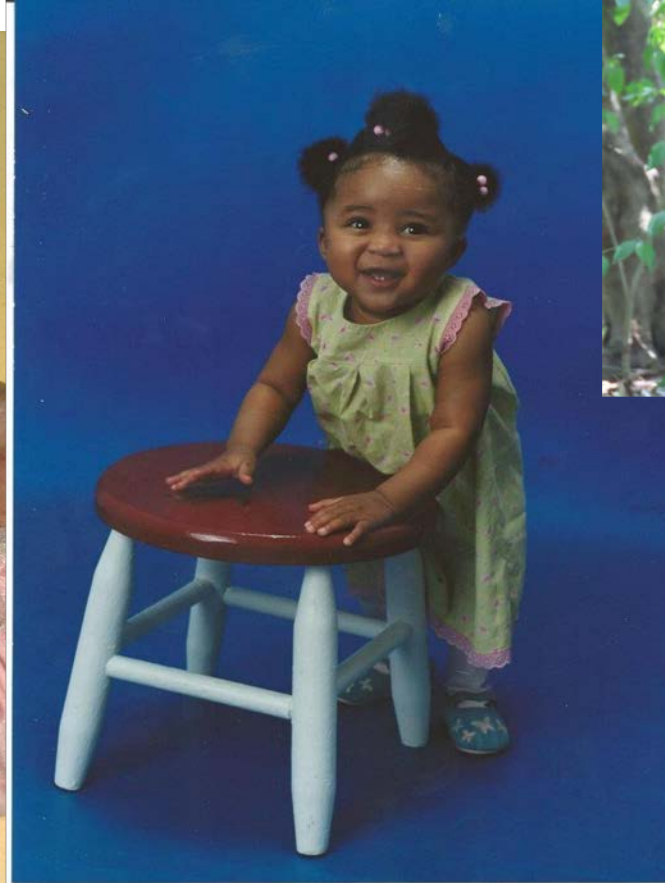
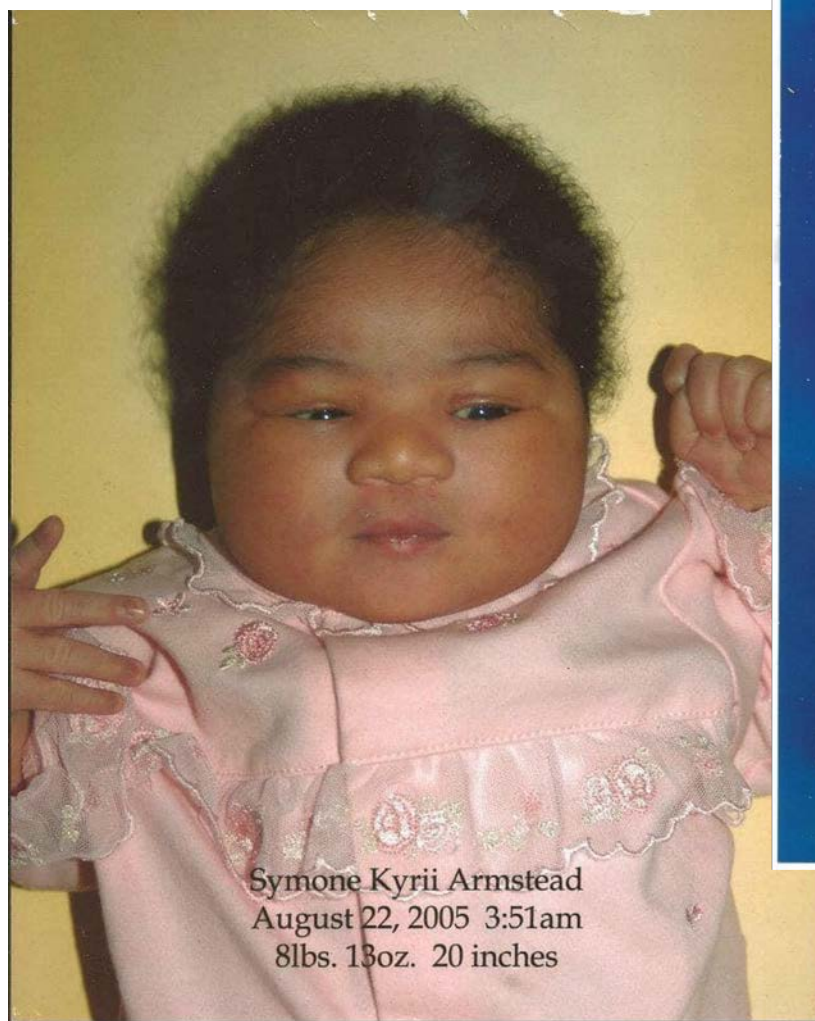
SUPPORTS

- Utilize a fatal diagnosis birth plan
- Guide them through labor and delivery the same way you would if there was no adverse outcome expected.
- Find out if a c-section would allow for additional time with the baby and time to make memories.





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For this child we have
prayed...

BOSTON LATIN ACADEMY

CLASS OF 2023



The NICU is an intensive care unit specializing in the care of ill and premature newborn infants.



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NURSERY LEVELS



1. Well Newborn Nursery
2. Special Care Nursery
3. Neonatal Intensive Care Unit
4. Regional Neonatal Intensive Care Unit

DAILY Absolute

COMMON CAUSES OF NICU DEATHS

- Premature birth (any birth before 37 weeks gestational age)
- Low birth weight (any baby weighing less than 5lbs 8ozs)
- Birth defects (heart defects, cleft lip, cleft palate, etc)

The logo features a circular emblem with a blue and pink butterfly design in the center, surrounded by a thin circular border.

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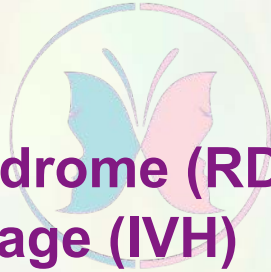
“Premature birth and low birthweight cause about 1 in 4 neonatal deaths (25%). Birth defects cause 1 in 5 neonatal deaths (20%).”



PAH Admaste
March of Dimes

PREMATURITY COMPLICATIONS

- **Respiratory Distress Syndrome (RDS)**
- **IntraVentricular Hemorrhage (IVH)**
- **Necrotizing Enterocolitis (NEC)**
- **Infections**



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BIRTH DEFECTS

- Heart Defects
- Lung Defects
- Genetic Conditions
- Brain Conditions



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BIRTH DEFECTS

- Heart Defects
- Lung Defects
- Genetic Conditions
- Brain Conditions



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EMOTIONAL & PSYCHOLOGICAL

- Families experience anticipatory grief
- Grief is compounded by medical trauma, disrupted bonding and the environment in the NICU.
- Guilt
- Anger
- Disorientation
- Isolation



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EMOTIONAL & PSYCHOLOGICAL

- **Some experience PTSD**
- **May need permission to feel, a space to remember and a community to heal.**



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SUPPORT

- **Provide normal postpartum care for birthing person**
- **Arrange for birthing person to stay at or near hospital when and where possible**
- **Help create a meal train for when family is at home**
- **Facilitate transport from one NICU to another**
- **Help create a money tree for expenses that family will incur while staying at, near or traveling to and from the NICU (ie. Parking, tolls, hotel, gas, food, etc.)**

SUPPORT

- **Help families make memories with the baby**
- **Help family arrange for childcare for additional children while they are at the hospital**
- **Make sure birthing person makes postpartum appointments**
- **Provide regular postpartum care for birthing person (ie. Rest, herbal baths, warming foods, faja, closing of the bones).**
- **Referral to online and in person support groups**
- **Refer to local breast milk bank to donate if desired**
- **Provide lactation cessation options**

WHEN A BABY DIES AT HOME



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CAUSES

- Sudden Infant Death Syndrome (SIDS)
- Sudden Unexpected Infant Death Syndrome (SUIDS)
- Shaken Baby Syndrome
- Infanticide
- Birth Illnesses
- Miscellaneous Illnesses



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LEADING CAUSES OF INFANT DEATH

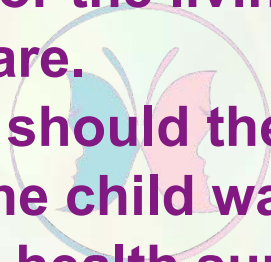
- **Congenital Malformations**
- **Disorders related to short gestation and low birth weight**
- **SIDS**
- **Unintentional Injuries**
- **Maternal complications**



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SUPPORTS

- Coordinate meal train
- Help with finding family for the living children to stay with when removed from parent's care.
- Help with home clean up should the police get messy
- Offer to clean the room the child was found in
- Connect family to mental health support
- Funeral planning
- Gently ask if they have thought about allowing you to clean the baby's room
- Pass along support group information
- Seek out mental health support as the support person



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INTEGRATIVE SUPPORT MODELS



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WHY INTEGRATIVE SUPPORT MATTERS

Can lead to:

- **Depression**
- **Anxiety**
- **PTSD**
- **Suicidal Ideation**
- **Disenfranchised grief**
- **Existential crisis**



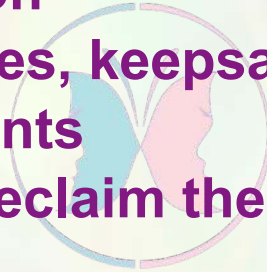
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CORE COMPONENTS OF INTEGRATIVE SUPPORT

- **Trauma Informed Mental Health Support**
 - Grief counseling, EMDR and peer led support groups
 - Addresses shame, guilt and identity disruption
- **Culturally Responsive Care**
 - Honors ancestral practices, Spiritual beliefs and Community rituals
 - Validates diverse expressions of grief
 - What does healing look like in your culture?

CORE COMPONENTS OF INTEGRATIVE SUPPORT

- **Ritual and Memorialization**
 - Naming ceremonies, keepsakes, storytelling and remembrance events
 - Helps the family reclaim their narrative and honor their child's legacy
- **Continuity of Care**
 - Support doesn't end
 - At discharge
 - After the funeral
 - In the days, weeks, months and years to come



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CORE COMPONENTS OF INTEGRATIVE SUPPORT

- **Continuity of Care**
 - **Includes the entire team**
 - **OBGYN/Midwife**
 - **Doula**
 - **Community Health Worker**
 - **Mental Health Clinician**
 - **Spiritual Leader**
 - **Community Advocate**



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"HOLDING SPACE MEANS TO BE WITH SOMEONE WITHOUT JUDGMENT. TO DONATE YOUR EARS AND HEART WITHOUT WANTING ANYTHING BACK. TO PRACTICE EMPATHY AND COMPASSION. TO ACCEPT SOMEONE'S TRUTH, NO MATTER WHAT THEY ARE. TO ALLOW AND ACCEPT. EMBRACE WITH TWO HANDS INSTEAD OF POINTING WITH ONE FINGER. TO COME IN NEUTRAL, OPEN FOR THEM. (NOT FOR YOURSELF.) HOLDING SPACE MEANS TO PUT YOUR NEEDS AND OPINIONS ASIDE AND ALLOW SOMEONE TO JUST BE."

~ Heather Plett

CONTACT ME!!!

EMAIL ADDRESS

nnekajhall@gmail.com

THANK YOU

