



A Look into the NICU

How early is too early to
predict future LCP needs?

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Meet the Presenters

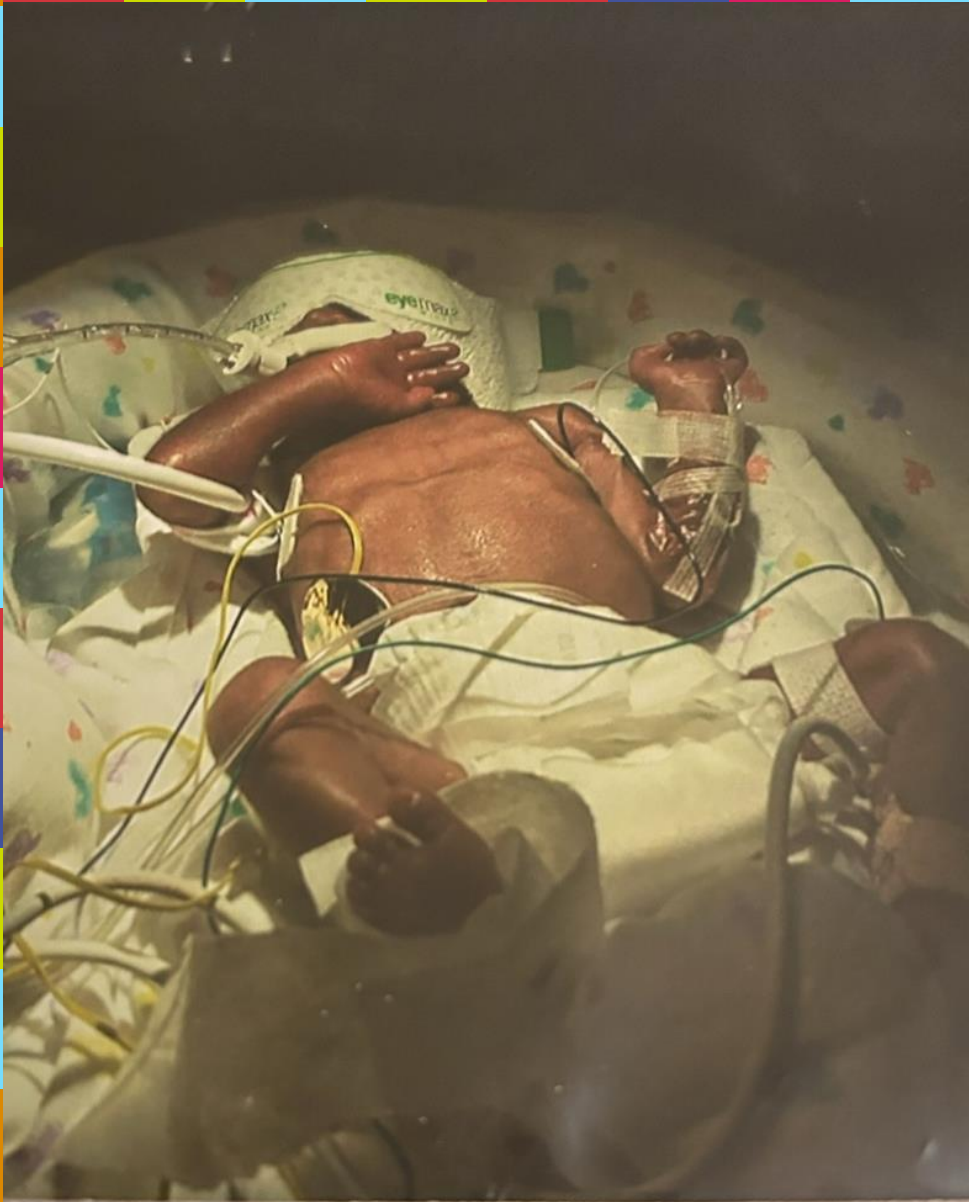
Kimberly – nurse for 18 years, background NICU, Life Care Planner for 8 years

Joda – nurse for 24 years, background Cardiology, NICU, Wonder Center for Medically Complex Children, Case Management, Soon to be a Life Care Planner



Objectives

1. Discuss the details of common neonatal lifecare issues/diagnoses.
2. Identify what the common problems with function and ADLs associated with the neonatal issues/diagnoses are.
3. Identify LCP recommendations early based on the early diagnoses and understand why the LCP recommendations are necessary.



What are common Life Care Issues in the NICU?

Neonatal Hypoxia

Periventricular Leukomalacia (PVL)

Necrotizing Enterocolitis (NEC)

Retinopathy of Prematurity (ROP)

Neonatal Hypoxia

Caused by lack of blood to the brain and body

This could be due to placental abruption, nuchal cord, complicated delivery

Lack of blood to the brain causes hypoxic ischemic encephalopathy (HIE)

Induce hypothermia and start the infant on a cooling blanket for 3 days to cool the brain a few degrees below normal body temperature

Research shows that cooling the brain may cause less brain injury

Hypoxic event could cause insult to other organs especially the intestines, so baby will be monitored closely

Can lead to cerebral palsy and seizure activity

Periventricular Leukomalacia (PVL)



Brain damage that occurs to the inner part of the brain (white matter)

May happen before, during, or after birth

More common in babies born prematurely (the more premature, the higher the risk)

Caused by lack of blood to the periventricular area of the brain

Periventricular area includes the ventricles where nerve fibers carry messages from the brain to the body's muscles

PVL may be accompanied by a hemorrhage in the area and can lead to cerebral palsy

Diagnosed by ultrasound of the head – 4 grades

Treatment is symptomatic and supportive

Necrotizing Enterocolitis (NEC)

Serious gut problem that inflames the intestinal tissue causing it to die

Can be caused by prematurity, low oxygen levels at birth, infection

Mild cases – IV fluids, NPO, antibiotics

Severe cases – surgery, stoma care, ostomy bag

Some babies undergo a 2nd surgery to reconnect the intestines

Can cause short-gut syndrome depending on how much of the intestine is destroyed

Short-gut kids will need lifelong care to get the right nutrition to grow

Can also cause growth failure and developmental delays

Retinopathy of Prematurity (ROP)



Eye disease in premature babies or low birth weight babies

ROP happens when abnormal blood vessels grow in the retina

Caused by too much oxygen therapy, infection, prematurity (blood vessels in retina develop in 4th month of pregnancy and finish developing in 9th month)

Stage 1 (mild - observe) to Stage 5 (severe – vision loss/blindness)

Stage 4-5 often need surgery

Early stage can get worse quickly so close follow-ups are important

Other treatment includes laser treatment, injections

Prone to eye problems as age including retinal detachment, nearsightedness (glasses), amblyopia, crossed eyes

Systems that could be affected by prematurity

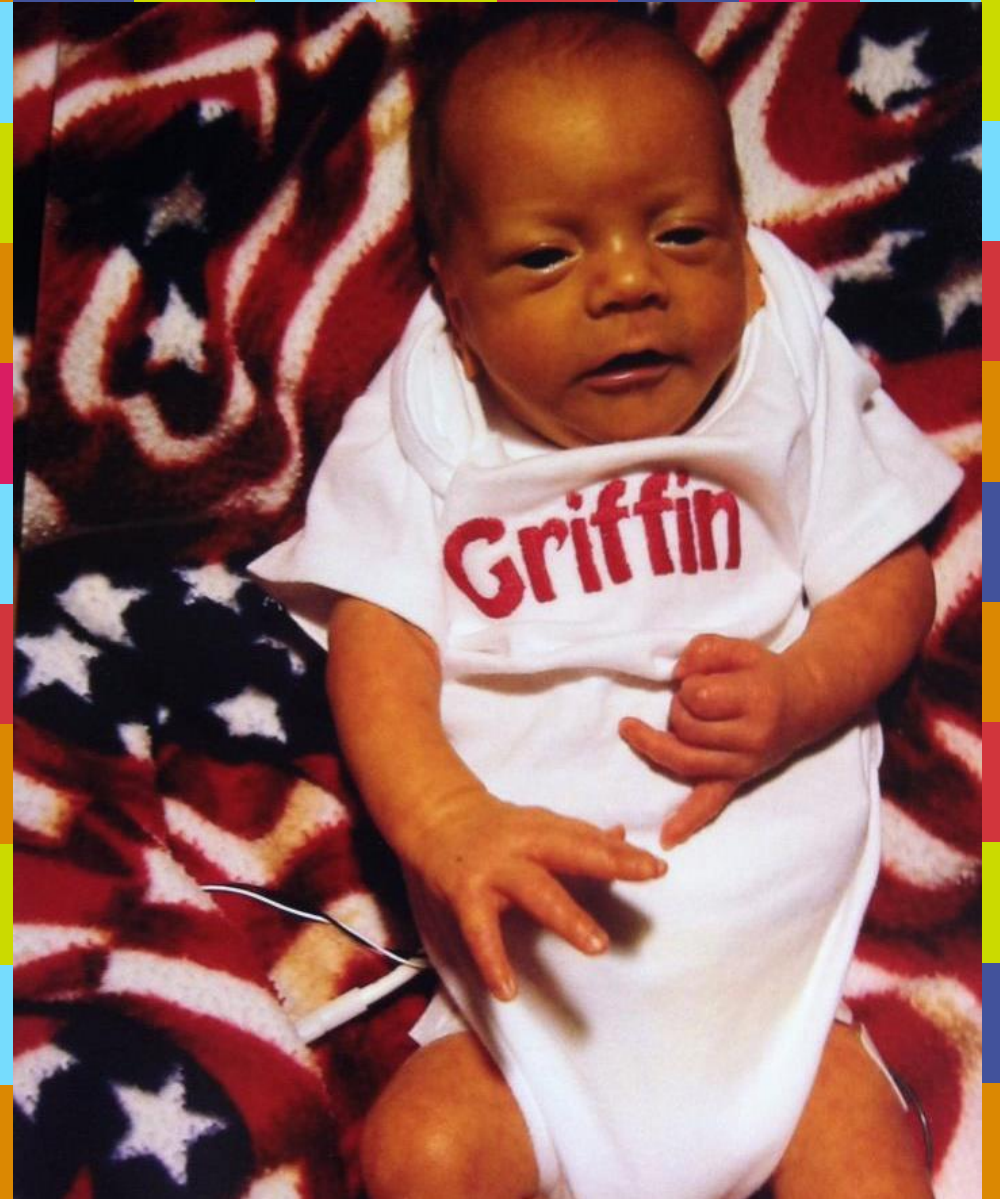
Pulmonary – apnea, increased asthma risk, poor lung function

Digestive – short-gut syndrome, increased risk for liver failure

Renal – increased risk for kidney disease

Cardiovascular – increased risk for hypertension, ischemic heart disease, heart failure

Central Nervous System – increased risk for autism, mood disorders, intellectual disability





What are common problems with function and ADLs associated with these medical diagnoses?

Dysphagia
Respiratory issues/apnea
Reflux
Stoma care

Vision and hearing impairments
Coordination problems
Delayed growth
Social-emotional problems

Behavior problems
Motor disorders
Delayed cognitive development
Spasticity



What to expect in a Life Care Plan



Hypoxia/HIE/Cerebral Palsy

Case Study: MVA, born 35 weeks due to placental abruption, HIE, now age 6, developmental delay, dysphagia – G-tube dependent, visual impairment, spastic quadriplegic CP with seizure activity, unable to lift head, unable to sit independently, incontinent.

Hypoxia/HIE/Cerebral Palsy

Medical Care

- Neurologist
- PM&R
- Orthopedist
- Primary Care
- Ophthalmologist
- Gastroenterologist
- Nutritionist
- ENT
- Pulmonologist
- Surgeon

Surgeries

- Botox
- Tendon lengthening of UE/LE
- Tonsillectomy/adenoidectomy
- Scoliosis surgery
- G-tube
- Intrathecal Baclofen
Pump/refills/replacement

Therapies

- PT/OT/Speech
- Psychological Evaluation
- Developmental Psychological
Exam
- Family Counseling

Hypoxia/HIE/Cerebral Palsy

Diagnostics

- X-rays, spine, hips, neck, knees
- MRI, extremities
- MRI, spine
- Bone density scan
- Swallow study
- Sleep study
- EEG
- Labs – depending on what meds

Orthotics

- AFOs
- Orthoses – wrist, elbow, knee
- Hip abduction orthosis
- Cervical collar
- Spinal orthosis
- OT eval with orthoses fitting

Medical Supplies

- Gloves
- Diapers child/adult
- Wipes child/adult
- Incontinence pads
- Suction machine/supplies
- G-tube supplies
- Glasses

Hypoxia/HIE/Cerebral Palsy

DME

- Chill-out chair
- Therapy net swing
- Pediatric stander
- Roll-in Shower chair
- Electric bed
- Hoyer lift
- Custom wheelchair/accessories
- OT eval for wheelchair replacements

Home Care/Transportation

- Skilled nursing care vs unskilled care
- Handicap parking permit
- Purchase/replacement of wheelchair accessible vehicle

Other

- Nurse Case Manager



NEC/ROP

Case Study: MVA, born at 32 weeks, got NEC at 2 weeks of age, had surgery to remove necrotic bowel (lost 20cm), on parenteral IV fluids for 5 months, required extensive oxygen therapy while recovering. She was diagnosed with ROP stage 3 and had laser surgery while in the NICU. Finally on feeds and discharged with ostomy. Short-gut syndrome, delayed growth and stoma care, otherwise normal development.

NEC/ROP

Medical Care

- Primary Care
- Gastroenterologist
- Nutritionist
- Surgeon
- Ophthalmologist

Medical Supplies

- Gloves
- Ostomy supplies
- Glasses

Surgeries

- Reanastomosis

Other

- Nurse Case Manager

Diagnostics

- X-rays, abdomen
- CT, abdomen
- Liver function panel
- Labs, electrolytes



Griffin

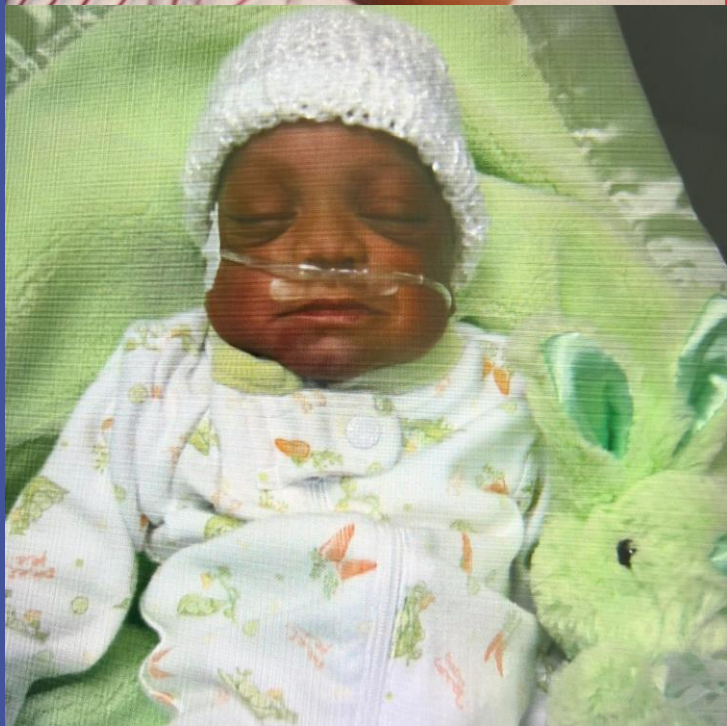
Born at 28 weeks, PVL grade 4, had NEC, parenteral nutrition for most of his NICU life, liver damage, cerebral palsy with spasticity, G-tube dependent, dental caries, transitioned from stroller to wheelchair, arm and leg orthoses, passed away at age 3



Exceptions (Miracle babies)



Jarundus
25 weeks
1 lbs, 10 oz
ROP stage 3
PVL grade 2
Went home on NC O₂





17 years old, 6'0" 278 lbs

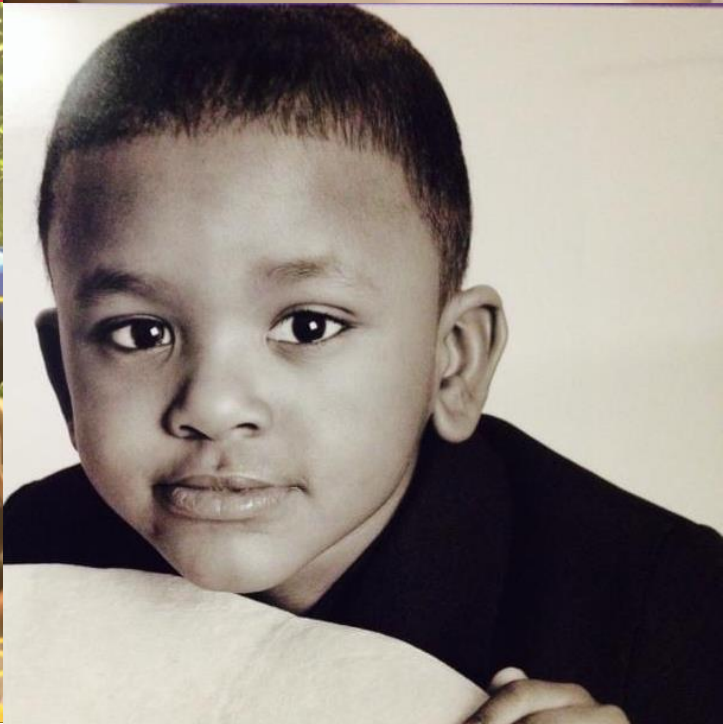
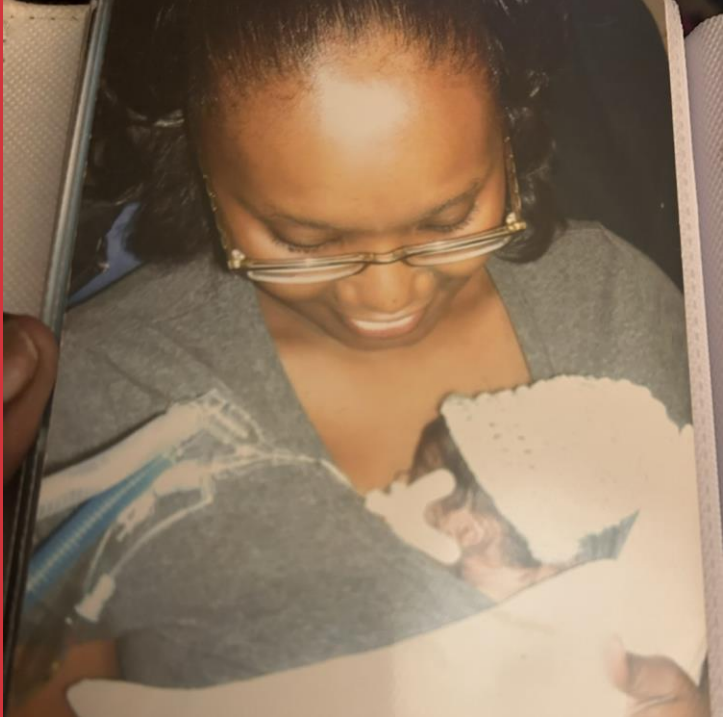
Graduates in May!

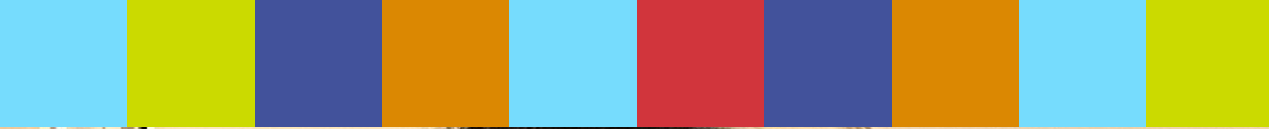
Had follow-up visits with Neurology, Pulmonology, and Ophthalmology first 3 years of discharge. Weaned off Oxygen first year, everything resolved, and he never had any other issues.

Exceptions (Miracle babies)



Darrell
25 weeks
1 lbs, 15 oz
Heart surgery to close
PDA at 2.5 months old





16 years old, 5'8" 125 lbs

Sophomore in High School taking culinary arts for dual college credit, just started driving

No complications from prematurity

Thank you Questions??

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Resources

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