

# Premature Infants

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## I. Classifications of high risk newborns

### i) Classification according to size

- (1) Low birth weight- birth weight lower than 2,500 grams (5 1/2 pounds)
- (2) Very low birth weight (weighing less than 1,500 grams (3 1/2 pounds).
- (3) Extremely low birth weight (weighing less than 800 grams (1 1/4 pounds)

### ii) Classification according to gestational age

- (1) Gestational Age Assessment—calculated from the projected birth date
  - (a) Infants born before 37 weeks' gestation are considered to be premature.
  - (b) The current edge of viability is represented by infants born at 23 to 25 weeks' gestation. Neonatal survival of infants at 23 weeks gestation ranges from 11% to 30%. 30 to 50% of these infants have moderate to severe disability (Kelly, 2006)
  - (c) Very premature-
    - 2 % of all premature infants are believed to be very premature (born before 32 weeks' gestation).

## II. Incidence of Prematurity

### i) Size of the Problem

- (1) About 13% of all births are premature births
- (2) Minnesota's rate of low birth weight births approximately 6.3%--contributing factor is multiple gestation and increased age of mother and father.
- (3) Counties 50% over state average for LBW or preterm births: Big Stone, Grant, Hubbard, Kittson, Rock, Swift, Traverse, and Wabasha (2001)
- (4) Low birth weight infants are at least 20 times more likely to die than heavier babies and more likely to suffer long-term illnesses, neurological and developmental disabilities.
- (5) Older gestational age, higher birth weight, female, born singleton rather than multiple birth, and baby's mother given steroid medication during pregnancy has direct relationship to survival without disability (NICH, 2008)  
<http://www.nichd.nih.gov/about/org/cdpm/pp/prog-epbo/> to access the on-line tool.

## III. Causes of premature births

- i) Abnormalities of the mother's cervix or uterus
- ii) High number of multiple pregnancies
- iii) Placental abruptions and placenta previa
- iv) Having too much or too little amniotic fluid
- v) Diabetes

- vi) High blood pressure
- vii) Maternal malnutrition—leading to poor weight gain
- viii) Fibroids
- ix) Increased prevalence of substance abuse—smoking and drugs
- x) Adolescence—20% of pre-term births accounted for by adolescents
- xi) More women having babies at older ages → more likely to have pre-term births and most recently > age of father = increased chance of preterm birth.
- xii) African American

#### **IV. Outcomes of prematurity at a glance—the data is mixed**

- a. Results of studies over past 20 years indicate:
  - i. Survival rates and outcomes have dramatically improved in recent decades but morbidity and mortality are still significant
  - ii. Infants born prematurely are at increased risk of growth problems, developmental delays, and complex medical problems
  - iii. Half of all babies born at 20-25 weeks gestation have some disability at 30 months of age, with a quarter having severe disabilities.
  - iv. Extremely premature babies are also at risk for later behavioral and educational difficulties.
  - v. 10% to 50% of infants born before 30 weeks' gestation or with extremely low birth weight have severe neurologic and developmental disabilities
- b. Results of studies over past 3 years indicate:
  - i. The Journal of the American Medical Association (2007) *Change in cognitive function over time in very low-birth-weight infants* concluded that most Very Low Birth Weight 'children had improvement in verbal and IQ test scores over time.
  - ii. *Outcomes of Extremely Low Birth Weight Infants (500 to 999 Grams) Over a 12-Year Period* concluded that 'low birth weight was not associated with abnormal outcome' and they had 'no neurologic, neurosensory, or cognitive deficits. (Pediatrics, 2007).

#### **V. U.S. Health Care System's Resources addressing high risk neonates**

- a. The U.S. tends to intervene more aggressively with at-risk infants- babies born after 24 to 25 weeks of gestation are mature enough to survive---but will need prolonged period of intensive care.
- b. In the US, neonatologists tend to view the lower limits of intervention at around the 500 gram, 24-week gestation period, while other Western nations don't initiate measures if infant under 600 grams—in Britain and Sweden, the lower level of intervention is at 750 grams and the infant's prognosis is a key factor in determining whether extraordinary care is continued.

- c. The most profound difference between America and other national approaches is found in long-term care, with US providing less than other nations. At age of 18 y.o. many of these kids lose ability to retain services
- d. In Sweden, the state provides specialized housing, equipment, surgery, and therapeutic day care for the at-risk-child, and offers parents 60 days paid leave from their jobs to stay with their child in the hospital.

## **VI. A Different Beginning: Resuscitation Equipment found in Delivery Room**

1. Radiant warmer
2. Suction
  - a. Bulb suction—most basic—used for nose and mouth
  - b. Wall suction—catheter...passed into nose, mouth, throat, and sometimes stomach
3. Oxygen delivery
  - a. Free flow—pointing at face
  - b. Bag and mask—using mask that fits over baby's nose and mouth
4. Endotracheal Tube
  - a. Small thin plastic tube placed directly into baby's trachea—connected either to oxygen bag or a ventilator
5. Emergency Medications
  - a. Med's used to stimulate heart rate, increase blood pressure, correct chemical imbalances in blood. Some administered through ET tube but others through IV into blood stream.
  - b. Caffeine frequently used because given via IV –stimulates part of brain that controls breathing

## **VII. Resuscitation Activities**

1. Warmth
2. Breathing
3. Heart rate
4. Endotracheal intubation.
5. Umbilical catheter placement-
  - a. Arterial catheter
  - b. Venous Catheter
6. Apgar Scoring
  - a. At one minute of age, again at 5 minutes and every 5 minutes during resuscitation, baby is assessed and given a number score to reflect general condition.

- i. Very premature babies receive lower scores because they are immature and unable to respond with loud crying because they do not have strong muscle tone

### **VIII. Admission into the NICU**

1. First hour priorities
  - a. Stabilization
  - b. Temperature control
  - c. Breathing
  - d. Maintaining adequate blood sugar level.
  - e. Injection of Vitamin K to prevent potential bleeding difficulties
  - f. Antibiotic ointment—placed in eyes to prevent infection
2. Basic NICU tests-
  - a. X-Rays:
  - b. Blood gases- analyze levels of oxygen, carbon dioxide—used to adjust ventilator and oxygen needs
    - i. Arterial –from artery (umbilical)
    - ii. Venous
    - iii. Capillary—heel stick
    - iv. Typical blood work
      1. CBC and Blood culture (detect infection)
      2. Hematocrit and hemoglobin—baby’s ability to supply oxygen to body tissues
      3. Blood glucose—determine blood sugar level
      4. Electrolytes- determine balance of body chemicals
  - c. Urine tests
    - i. Kidneys are sensitive to changes in body
    - ii. Strict I & O
    - iii. Urinalysis—acidity, sugar, protein, blood
    - iv. Culture and sensitivity—infection

### **IX. Typical NICU Equipment—Overwhelming sensory input for parents**

- a. Radiant warmer
  - i. Used to stabilize temperature
  - ii. Incubator: keeps baby warm with moistened air in a clean environment away from noise, drafts, infection, and excess handling.
- b. Cardio-respiratory monitor
  - i. Tracks heart rate and rate of breathing

- ii. Monitor picks up electrical activity of baby's heart, transmits info onto screen and digitally displays number—alarms will sound when vital signs go above or below a certain limit
- c. Blood pressure monitor- Small plastic cuff wrapped around arm or leg and/or taken through umbilical arterial line
- d. Intravenous line
  - i. Infants given IV fluids right after birth—including additional sugar plus body chemicals such as sodium and potassium to give baby energy because can't take in PO.
  - ii. Hyperalimentation fluids started soon after birth to support growth (contain sugar, protein, fat (lipids), minerals, and vitamins... often a PICC line is started
  - iii. IV pumps or infusion pumps are crucial—most babies have one or more IV or art lines...fluid must be regulated very carefully---all the way down to amounts of 0.1 cc per hour (about 1/30 of a teaspoon per hour).
- e. Umbilical Lines
  - i. UAC—may be threaded into the aorta through one of the two arteries
  - ii. If umbilical arterial line used, line will be connected to a transducer so that baby's blood pressure can be displayed on the cardiac monitor.
  - iii. Normal range for baby's blood pressure depends on gestational age, size, activity level, and condition.
- f. Pulse oximeter
  - i. Measures transmitted light to estimate how much oxygen is in blood.
  - ii. Doesn't indicate the exact amount of oxygen in blood but used to determine amount of oxygen needed.
  - iii. Used to assess how well baby is using oxygen available to her.
- g. Transcutaneous Monitor
  - i. Noninvasive system for monitoring oxygen and carbon dioxide levels in the blood stream.
- h. Phototherapy lights or “bili lights” are used when babies are jaundice If a molecule called bilirubin is in the blood—it was discovered that wavelengths of light (in the blue part of the spectrum) can cause a chemical reaction that converts bilirubin into a harmless form as blood passes through the skin. Bili lights do not deliver any ultraviolet light, so no toxic effects, but as safety measure, babies eyes are shielded when under bililights.

## **X. Basic Information about Oxygen**

- a. Supplemental oxygen is any amount exceeding 21% (amount of oxygen in room air)
- b. Always humidified and delivered in several ways
  - i. Hood or tent—usually for larger infants

- ii. In an incubator—used for infants requiring low levels of supplemental oxygen (about 25%) –opening portholes can dilute the amount of oxygen being received (group cares)
- c. Oxygen cannula—used to provide extra oxygen but baby breathing well on own. Cannula used when feeding, physical therapy, bathing, etc
- d. Continuous positive airway pressure (CPAP) Baby breathes on own but machine keeps steady supply of air/oxygen under pressure pushing into lungs
  - i. Helps keep the tiny air sacs in the lungs from collapsing after each breath, reducing the effort the baby must use to breathe
  - ii. Can be delivered through baby’s nose or through ventilation
- e. Mechanical ventilation—delivers controlled mixture of air and oxygen, pressure with each breath and a certain number of breaths per minute. The “stiffer” a baby’s lungs, the higher the pressure must be to move the air/oxygen through the air sacs into the bloodstream.
- f. Very sick babies require a high level of oxygen (up to 100%) a high pressure and a high rate
  - i. Ventilator attached to baby’s ET tube
  - ii. Babies can take breaths on own while on ventilator
  - iii. ET tube removed called extubation
  - iv. Extubation can happen routinely
  - v. Parents can hold infant while on a ventilator.
- g. Very sick babies might be put on a “high frequency oscillatory ventilator” –This ventilator inflates and deflates baby’s lungs like a set of billows, the oscillator keeps the lungs open with a constant positive end-expiratory pressure (PEEP) and vibrates air at a very high rate (up to 600 times/second). The vibration helps gases to quickly diffuse in and out of baby’s airways without need for “bellows” action which may damage delicate lung structure.

## **XI. Common Reactions of parents to first visit in NICU**

1. Fear
2. Anger
3. Guilt
4. Loss
5. Powerlessness
6. “Fish in a tank feeling”

## **XII. Infant Capabilities- Parent Education**

1. Can my baby see?
  - a. Infant's vision is least well developed part of sensory system at birth. Even in term infants, areas in the retina of the eye responsible for sharpness of vision are incompletely developed as are the nerve fibers in the optic nerve.
  - b. Infants have poor eyesight and little ability to focus. Probably don't see color until 2 to 3 months of age
  - c. Fetus's eyelids fuse during week 10 of gestation and remain fused until around 26 weeks---so infants eyelids may be fused together---they will eventually open on their own
  - d. Important to look face-to-face 6 to 10 inches away.
  
2. Can my baby hear?
  - a. The ears begin to develop in 4<sup>th</sup> week of gestation
  - b. By 27 weeks, ears functionally developed
  - c. Hearing sensitivity improves with development---preterm infants response to sound is less consistent than term baby
  - d. Although preterm can hear quite well, the auditory system still vulnerable
    - i. Loud sounds may not only harm hearing, but also produce physical stress (changes in heart rate, breathing, oxygen consumption
  - e. NICU environment
  
3. Touch and Pain
  - a. Sense of touch is first to develop in fetus. Nerves carrying feelings to and from the extremities form during the 5<sup>th</sup> week of gestation and sensory nerve endings in the skin form early in gestation---baby has an acute sense of touch, even at 25 weeks gestational age.
  - b. Sense of touch highly developed in preterm infants
  - c. Stimulation—face, area around lips, hands are sensitive to touch
  - d. Quiet baby with firm, gentle stroking—or firm pressure
  - e. Give sense of security by providing boundaries—similar to inside of uterus
  - f. Crying, difficulty sleeping, agitation, frowning, and clinching fists are common behavioral responses to pain as is drop in oxygen saturation, increased heart rate, breathing faster, elevated blood pressure
  - g. Interventions to relieve pain—positioning and medications.
  
4. Behavioral States
  - a. Six different levels of awareness or behavioral states

- i. Pre-term babies exhibit same behavioral states as other babies but transition not as clearly defined
  1. Deep sleep
  2. Light sleep- Most preterm babies spend most of their time in light sleep.
  3. Drowsy-
  4. Quiet alert- This is ideal state for interacting with your baby because she is receptive stimulation. Preterm babies can reach quiet alert state, but often only for seconds. As baby matures, periods of quiet alertness will increase.
  5. Active alert- Baby's activity increases---reacts to external stimuli, may startle and thrust arms and legs. Breathing is irregular may or may not be fussy. During this state baby unable to focus attention, has a decreased tolerance for continued stimulation. If speaking to baby or attempting to make eye contact—baby may escalate to crying...if lower voice, or discontinue interaction, may return to quiet alert state
  6. Crying – Breathing is irregular, shallow and rapid---baby cannot cope with surroundings.

## 5. Infant Cues

### a. Invitation Cues—

- i. Relaxed appearance (especially of arms and legs, a “bright look? And regular, slow, breathing. Some babies move their hands to their mouth.
  1. Have a stable pink color
  2. Move head and limbs smoothly
  3. Maintain position without squirming
  4. Hold feet one on top of or next to the other
  5. Hold fingers or hold one hand in the other
  6. Suck on fingers or fist
  7. Grasp blankets or caregivers fingers
  8. Curl up into a ball on one side
  9. Be able to use help offered by a caregiver to stay calm (use pacifier, hold onto caregiver's hands)
  10. Enjoy being held, calm when held
  11. Focuses eyes; watches faces or objects
  12. Makes an “ooh” face by pursing lips

### b. Stress Cues- Cues that infant has had enough, needs a short break

1. Changing breathing (increased rate, pauses, gasping for air)
2. Changing color from pink to pale, white, or blue

3. Hiccupping, gagging, or grunting
  4. Spitting up
  5. Straining as if to have a bowel movement
  6. Startling, tremoring, or twitching body, limbs, or face
  7. Coughing, sneezing, yawning, or sighing
  8. Squirming
  9. Having limp limbs, neck, face, or trunk
  10. Having stiff legs, arms or fingers
  11. Sticking out tongue
  12. Arching back and neck
  13. Having a dull, tired, glassy-eyed appearance; staring, looking away—having
  14. Crying weakly or being irritable
  15. Suddenly going to sleep or fussing
  16. Sleeping restlessly, with jerky movements or sounds, whimpering, or fussing
  17. Displaying frantic, ongoing, disorganized activity that baby cannot control.
- c. Mixed messages
- i. Baby may appear to be in quiet alert state, ready to interact, yet at the same time be hiccupping---this mixed message frustrates parents.  
Really just have to look at whole picture
6. Interacting with infant
- a. Follow baby's lead
  - b. Introduce only one stimulus at a time so baby can concentrate and attend more effectively
7. Positioning
- a. Helps to keep infant "organized"
  - b. Preterm infant's muscle tone is different from that of term infant.
  - c. Intervention- Flex baby forward and bring her arms and legs to center of her body and body containment by swaddling and nesting helps baby feel safe and secure.
8. Kangaroo Care
- a. When infant is stable can try this skin-to-skin against chest technique.
  - b. Mothers who provide kangaroo care tend to have more success with lactation and a better milk supply—even if kangaroo care is a few minutes a day...
  - c. Buehler et al (1995) 41/70 electrophysiological features had significant differences between infants having Kangaroo care and those not. The 41 significant regions included the frontal lobe (18), temporal region (12) and the last 11 were the central, occipital and parietal regions.

- i. The frontal lobe is associated with state organization and attention—suggesting that this intervention may support a more full-term like development of the frontal lobe while at the same time support state and attention organization outside of the womb.
- 9. Relationship of maternal depression and infant health outcomes
  - a. Depressed mothers are more likely than other children to have behavior, cognitive, socio-emotional problems, academic difficulties and health problems.
  - b. Among families receiving welfare, children of depressed mothers have, on average, lower scores on mathematical achievement tests than other children. Depression among mothers has also been linked to delays in cognitive and motor development among children ages 28 to 50 months.
  - c. Approximately 70 to 80% of new Mom's experience post-partum depression, usually within 1-3 days after delivery. (NIMH, 2007)
  - d. Watch for post-partum depression and encourage referral.

#### 10. Sleep

- a. Approximately 80% of a neonates day is spent in active REM sleep and the remainder in quiet non-REM sleep and wakefulness. By 5-6 months of age, human infants spend only 20-30% of time in REM sleep with remainder of time spent equally in non-REM sleep and wakefulness.
- a. Still learning a lot about developmental requirements, but high percentage of time spent in REM sleep during critical period in human brain growth and maturation in early postnatal life may indicate that the neural activity controlled by REM state mechanisms may be developmentally functional and contribute directly to physiological and structural brain maturation.
- b. The short and long term implications of sleep disruption just beginning to be understood.
- c. Studies in neonatal animals indicate that suppression of REM sleep can lead to behavioral, anatomic, and biochemical deficiencies, including respiratory, that extend into adulthood. Neonatal active sleep may be a critical factor in the normal development and expression of respiration.

### **XIII. Feeding**

- a. Premie babies too small and weak to suck on breast or bottle. Gavage feedings allow breast milk or formula to be fed every 3 hours...small babies sometimes fed continuously so stomach is never overfilled
- b. Breast milk
- c. Formulas
- d. Feeding intolerance

#### XIV. Common Medical Problems of Premature Infants

- a. Gastroesophageal Reflux (GER or Reflux)
  - i. The muscle at the top of the stomach (lower esophageal sphincter) naturally opens and closes to allow swallowing, burping, and vomiting.
  - ii. Refluxing occurs when the stomach acid and partially digested food flow back up through the LES into the esophagus.
  - iii. Symptoms of reflux
    1. Spitting up frequently (more than 2 times a day)
    2. Fussy often throughout the day (specifically before, during or after eating)
    3. Refusing to eat
    4. Taking only small amounts
    5. Back arching with feeding, fighting feeding, is
    6. Choking, bradycardia, apnea during or after eating, skin color changes
    7. Parents will say “she acts like it hurts to eat” or “it seems like she is in pain.
  - iv. Diagnosis of GER
    - UGI
    - Milk scan similar process
    - 24 hour pH probe
    - Endoscopy- under anesthesia—tube put into esophagus—tip allows dr. to look for reddened or damaged areas
  - v. Treatment
    1. Thickened formula
    2. Medications- Zantac or Tagamet—decreases or blocks production of acid
    3. Reglan- improves digestion
    4. If medical intervention not successful---surgical→ purpose is to create an artificial sphincter at the top of the stomach by wrapping a small part of the stomach around the esophagus.
  - vi. No research suggesting a causal relationship between GER and apnea.

- vii. Head of bed elevation does not have any effect on the incidence or symptoms of GER, thickened feeds are helpful in reducing symptoms and metoclopramide may have some benefits over placebo (Craig et. Al, 2004).
  - viii. With or without intervention GER 's occurrence will decrease as the child matures.
  - ix. National parent support group PAGER (Pediatric Adolescent Gastroesophageal Reflux Association, Inc at <http://www.reflux.org>
- b. Apnea of prematurity**
- i. Apnea of prematurity is defined as a respiratory pause for at least 20 seconds, or a pause associated with bradycardia, change in tone, abnormal movements, or oxygen de-saturation, in an infant born before 37 weeks' gestation.
    - 1. **Caused by:**
      - a. Immature nervous system—may not have the reflex to breathe when oxygen level is too low
      - b. Fatigue—breathing is hard work and preemies' muscles are not yet fully developed—even feeding tires the baby
      - c. Feeding problems—a baby may stop breathing because it hasn't yet learned to coordinate suckling, swallowing, and breathing
  - ii. **Treatment**
    - 1. Caffeine levels may be monitored and adjusted while the infant is experiencing significant apnea of prematurity
    - 2. Many NICU's discontinue caffeine supplementation by 34 weeks postconceptual age—theophylline is also given
    - 3. An apnea monitor should be given upon discharge from the NICU for pre-term infants at increased risk of apnea episodes upon discharge.
    - 4. If infants are event free, discontinuation of pharmacologic therapy should be considered at 40 weeks' adjusted age.
    - 5. Home monitoring is continued until the infant is 43 weeks' adjusted age and free of extreme episodes (AAP)
    - 6. Parents need to be taught to:
      - a. Mildly stimulate
      - b. Adjust feeds so they are shorter or more frequent
      - c. May sometimes gavage
      - d. CPAP
    - 7. Supine sleep position not prone positioning is recommended at home regardless of home monitor use.
    - 8. There remains no proven association between apnea of prematurity and SIDS.
    - 9. Fortunately, apnea goes away as baby matures. Once it goes away, there are no long-term effects

**c. Respiratory Distress Syndrome (RDS)**

i. Role of surfactant

1. Many babies born prematurely have not yet started making surfactant. Surfactant is a substance that helps keeps lungs open when breathing.

2. Treatment

a. RDS is treated with artificial surfactant

b. Baby can be given oxygen with a nasal cannula, or a CPAP (continuous positive airway pressure)...keeps alveoli from collapsing. This may be used with or without supplemental oxygen.

c. Ventilation---does work of breathing—ventilator used until baby’s lungs are making surfactant and baby is strong enough to breathe.

d. Long term effects-

Increased sensitivity to lung irritants, increased risk of respiratory infections, lung damage—leading to BPD.

**d. Bronchopulmonary dysplasia**

i. Increases with decreasing birthweight and lower gestational age.

ii. Fifty to 80 percent of infants born weighing less than 900 g (31.75 oz) develop bronchopulmonary dysplasia.

iii. Risk of BPT increases with decreasing birth weight and lower gestational age

iv. Occurs more often in babies requiring ventilation for a long period of time.

v. These infants are more susceptible to pulmonary infections and suffer from episodes of respiratory distress and wheezing, which can be indistinguishable from a respiratory infection.

vi. Treatment may include:

1. bronchodilators,

2. diuretics,

3. oxygen

4. antibiotics

vii. Outcomes

1. Children with bronchopulmonary dysplasia continue to show poor lung function until adolescence, which is when lung function typically becomes normal.

2. These infants are more susceptible to pulmonary infections and suffer from episodes of respiratory distress and wheezing, which can be indistinguishable from a respiratory infection.

3. Usually sent home on oxygen with a pre-prescribed oxygen flow rate—sometime can increase flow rate when baby is sleeping or when baby has a cold
4. Very important to tell parents about sensitivity to lung irritants such as smoking in the same location and air pollutants—crying is stressful so attempt to meet babies needs.
5. Protect baby from dust, pollution, and other lung irritants as much as you can.
6. Keep up to date on vaccinations. Keep family members healthy, Have annual flu shot, keep infant away from day care centers and crowds.

e. **Necrotizing Enterocolitis (NEC)**

- i. A serious intestinal infection that starts after feedings have begun
- ii. There are between 2000 to 5000 new cases of NEC in the United States each year. (Goulet, 2004)

iii. **Treatment**

1. If this infection is suspected, x-rays are taken of the baby's intestine to observe for bowel swelling and/or gas in wall of bowel. X-rays taken every 8 to 12 hours to check for bowel rupturing.
2. Invading organisms will produce the gas. Feedings are stopped and baby is given antibiotics. If baby does have NEC—antibiotics are continued and baby not fed for 7 to 10 days---sometimes requires surgical intervention.
3. If the bowel wall ruptures—requires emergency surgery with a temporary ostomy in place to allow bowel time to heal. Stool from bowel will be collected into ostomy bag. If the intestinal diversion is in large bowel= colostomy.
4. If disease extensive, then amount of healthy bowel remaining may be quite short and unable to absorb enough nutrients and water from the stool=short gut → requires TPN.

f. **Intraventricular hemorrhage (IVH)** – bleeding in the small ventricles in the brain (sometimes called a bleed) which can be discovered during routine head ultrasounds.

- i. Diagnosis- baby shows signs of apnea, bradycardia, anemia, seizures, poor muscle tone, decreased activity and a bulging fontanel.
  1. Ultrasonography picks up bleeds and is done routinely on neonates

## 2. Classification of intraventricular hemorrhage

- a. Grade I- small amount of bleeding near the ventricle
  - b. Grade II- an extension of blood into the ventricle.
  - c. Grade III- enlargement of the ventricle as it fills with blood
  - d. Grade IV- enlargement of the ventricle and bleeding into the surrounding brain tissue.
- ii. Outcomes: Grades I-II germinal matrix-intraventricular hemorrhage tends to have little-to-moderate long-term impact on cognitive and neuromotor development after the neonatal period, while more severe hemorrhage is associated with less optimistic developmental prognoses such as severe cognitive disabilities and cerebral palsy

### g. **Retinopathy of prematurity**

- i. The retina (lining or screen at back of eye) begins to develop a supply of blood vessels at about 4 months gestational age. This process begins in the center of the retina and progresses outward. Blood vessel development is complete shortly after birth in term infants
- ii. With ROP, the normal growth of these blood vessels stops because of changes in concentrations of oxygen in the blood, combined with other factors. Rapid irregular growth of new vessels follows this pause.
- iii. Continuation of this rapid growth can lead to bleeding and to the formation of scar tissue which pulls on the retina. In most severe cases, retina may become detached, causing blindness
- iv. Retinopathy is usually only seen in babies less than 32 weeks gestational age, because most of the retinal vessels have developed by that age.
- v. Cause of problem still unknown—multiple risk factors:
  - 1. Complications of pregnancy, multiple gestation pregnancy, apnea, sepsis, nutritional deficiencies, unstable blood pressure, blood transfusions, IVH and Patent Ductus Arteriosus
- vi. Treatment
  - 1. Followed by ophthalmologist –exams begin 6 weeks after birth and will continue until blood vessel growth in eye is completed.

2. If blood vessel growth starts to cause problems, treatment with a laser or freezing (cryosurgery) can be done to keep retina from separating from the back of the eye.
3. In almost 75% of infants with mild ROP, the abnormal blood vessels do not cause scarring or damage to the eye. (Moshfeghi, 2007)

#### **h. Hearing Loss**

- i. The cochlea and peripheral sensory end organs complete normal development by 24 weeks of gestation.
- ii. The fetus can perceive, react to, and store auditory information by the 26<sup>th</sup> week of fetal life.
- iii. Maturation of the auditory pathways of the central nervous system continues up to and beyond.
- iv. Following birth, the middle ear and brainstem pathway continue development in two stages, the first between birth and about 6 months of age and the second from 6 months to about 5 years of age.
- v. By 6 months, infants demonstrate the beginnings of auditory discrimination.
- vi. Studies demonstrate that NICU graduates comprise half of the infants with abnormal hearing screens (Marshall, 2003).
- vii. LBW infants make up 19% of all children with hearing loss. Risk factors include
  1. Birth weight less than 1500 grams
  2. Use of mechanical ventilation for more than 5 days
  3. High bilirubin levels
  4. Apgar scores of 0 to 4 at 1 minute and 0 to 6 at 5 minutes
  5. Bacterial meningitis
  6. Administration of ototoxic medications while in NICU
- viii. Noise louder than 80 db (hallway phone, bedside monitor alarms) elicits a stress response including changes in respiratory, vascular, visceral, and motor systems. When noise becomes excessive, the neonate becomes overwhelmed—leading to

abrupt fluctuations in blood pressure, heart rate, respiratory rate, and oxygen saturation.

Intervention- before 6 months of age for infants with hearing loss helps to ensure language development comparable to their cognitive abilities through 5 years of age (AAP, 2000)

- ix. Studies have demonstrated that a speaker's voice must be at least 10dB louder than background noise for a 5 month-old to listen to his name. The infant does not respond to his name when it is spoken at 5dB above background noise until 13 months of age.
- x. Teaching parents prevention
  - 1. Limit intensity and number of sound sources- example car radios, cell phones, loud conversations, TV
  - 2. Strive to present one stimulus at a time
  - 3. Speak in a soft voice
  - 4. A quiet home environment protects sleep, supports stable vital signs, improves speech intelligibility, and promotes normal auditory development. (Goines, 2008)
- i. **Anemia**- Every pre-term baby becomes anemic (has too few red blood cells) during the first 2months of life. The baby loses blood from frequent blood tests and when her red blood cells bpdusystem that makes RBC's is immature. The infant cannot make new blood to replace the lost blood until 2 months after birth.
  - i. Most babies who are sick and need frequent blood tests, or who weigh less than 3 pounds at birth, will need a blood transfusion to keep the blood count normal.
  - ii. Premies are given extra iron in diet so when their bodies can make blood, they have plenty of iron for making new red blood cells.
  - iii. May also be given epogen to help stimulate red blood cell production.
  - iv. Anemia can cause low oxygen and glucose levels in blood which can cause the tissues and organs not to function properly.
  - v. Infants may appear pale and lethargic, have increase in apnea and/or bradycardia and not eat well.
  - vi. A low red blood cell count is the necessary stimulus to trigger production.

#### j. **Patent Ductus Arteriosis**

- i. PDA is the term that describes failure of a blood vessel present b/4 birth. Affects about 20% of infants weighing less than 1500 grams
- ii. When baby was in uterus, the blood circulating through the heart and lungs followed a path known as fetal circulation. **This path** allowed some blood to bypass the baby's lungs because the mother's lungs do the work of "breathing" for the baby.
- iii. Soon after birth, the two structures of the heart that allowed blood to bypass the lung (foramen ovale and ductus arteriosus) normally begin to close. But in some infants this doesn't happen. In the first few hours to days after birth, a patent ductus arteriosus directs blood away from the lung blood vessels, which are narrowed by the effects of respiratory problems such as RDS. This is called a right-to-left shunt..a right to left shunt allows blood without enough oxygen to travel to the body. As the baby's lungs recover from RDS, the blood vessels in lungs relax and blood can enter more easily. When that happens, a PDA will allow blood to flow back from the aorta into the lungs (a left-to-right shunt)
  1. Symptoms- Depends on size of ductus and amount of blood moving through
    - a. Signs of large opening include a murmur, an enlarged heart and respiratory problems
  2. Diagnosis—echocardiogram (ultrasound of the heart)
  3. Complications
    - a. Strain on heart because has to work harder to circulate blood
    - b. May lead to congestive heart failure—pulmonary edema
  4. Treatment
    - a. Surgical- suture around ductus ties it off.

#### **XV. Life as a parent in the NICU**

- a. Mothers interviewed by Wereszczak and colleagues cited difficulty obtaining accurate and consistent information and negative feelings concerning the care their infants received as examples of environmental stressors.
- b. Analyzes of parental responses on satisfaction with NICU care reveals common themes—needs for assurance, caring, communication, consistent information,

education, attention to the environment, follow-up care, pain management, participation proximity and support.

- c. To meet parental needs and those of their infant, health care professionals must acknowledge parental perspectives and consider how to minimize stress and intrusiveness while providing care. Mothers in particular want trust, support, and individualized attention calibrated to their emotional and psychological state at the time. Mothers developed more significant relationships with nurses than with other health care professionals, probably because nurses spend more quality time with mothers at their infants' bedside (Bruns and McCollum, 2002)
- d. Effective interventions that incorporate parents, particularly mothers, into care of their infants in the NICU is anecdotal and not tested.
- e. Heermann, Wilson, and Wilhelm (2005) conducted a qualitative study to explore and describe 15 mothers' experience of becoming a mother while their infants were receiving care in a level 3 NICU. Investigators found that mothers developed from an "outsider" to being an engaged parent along four continua:

#### Focus from NICU to baby

1. In the beginning, the NICU was in the foreground of the mother's attention and her baby was in the background. Attention focused on technology, the expertise of the nurses, and the language and culture of the health care providers. As mother developed along this continuum, mother could focus more attention on baby---but if change's in medical condition occurred, the focus would be back to the NICU environment.
2. Ownership: from their baby to my baby
3. Caregiving: from passive to active – Caregiving actions included touching, soothing and holding as well as physical care such as feeding, bathing, positioning, and diapering.
4. Voice-from silence to advocacy
5. Hurst (2001) found that mothers attempted to negotiate partnership relationships with professional caregivers but their actions were frequently misunderstood or disregarded
6. Thorne and Robinson (2006) proposed a 3 phase model to explain the development of relationships between families and health care professionals over the course of long-term illness. Qualitative study to describe health care

relationships from the patient and family perspective rather than from that of only health care professionals

- a. Phase One: Naïve Trusting
- b. Phase Two: Disenchantment.
- c. Phase Three: Guarded alliance

## **XVI. From Intensive to Intermediate Care**

### **a. Expanding parental role in care of infant**

- i. Working with baby's cues
- ii. Positioning for organization
  1. Flexed positions
  2. Boundaries
  3. HOB tilted up if baby spits up after feeding
  4. When held, position so arms, shoulders and back flex forward
  5. Diapering- teaching examination of skin, ointments such as A&D/Desitin
  6. Cord care
  7. Dressing, feeding, bulb syringe
  8. Massage- consider infant's tolerance for stimulation
    - a. Begin massage by "containing" baby—putting a firm hand on head or chest—holding arms and legs in flexed position.
    - b. Light massage tends to irritate very young preterm babies, but firm gentle stroking is good
    - c. Bathing-babies don't require a bath more than 2 to 3 times a week
    - d. Taking babies temp
    - e. Giving medications
    - f. Learning CPR

- g. Continue to monitor for complications
  - i. Apnea and bradycardia
  - ii. Infections
    - 1. Thrush and others
- h. Hernias
  - i. Inguinal
  - ii. Umbilical
- i. Reflux
- j. Anemia

## **XVII. Transition from NICU to home follow-up care**

- i. Discharge criteria for most NICU's is attainment of full nipple feeding, consistent weight gain pattern, resolution of apnea or bradycardia episodes, and temperature stability in an open crib.
- ii. Family Support

The transition from the neonatal intensive care unit (NICU) to home can be stressful. The American Academy of Pediatrics (AAP) recommends that planning for discharge from the NICU should include the following six critical components: (1) parental education; (2) implementation of primary care; (3) evaluation of unresolved medical problems; (4) development of the home care plan; (5) identification and mobilization of surveillance and support services; and (6) determination and designation of follow-up care.

### **iii. Weight Gain**

1. Growth can be limited by the preterm infant's endurance and coordination with oral feeds.
2. Weight gain of at least 20 to 30 grams (0.71 to 1.06oz) per day is desirable.
3. Children whose early catch-up growth was suboptimal and who are below the 10<sup>th</sup> percentile at 2 years of age are more likely to continue to be small at 5 and 8 years of age.

4. Infants born weighing less than 1500g may display increased weight for length in the early months after discharge; however, this is not an indication for restriction of intake.
5. To account for prematurity, growth and development monitoring should be done according to adjusted age (age in months from term due date). Premature infants should gain 20 to 30 g (0.71 to 1.06 oz) per day after discharge from the hospital.
6. Oral intake of greater than 165 kcal/kg per day may be seen in preterm infants fed ad lib during post-discharge periods of rapid growth. Growth parameters may be improved in the short term with the use of enriched preterm formula or breast milk fortifier. Those who don't get breast-milk fortifier are at risk for osteopenia.
7. <http://www.texaschildrenspediatrics.org/about/growthcalculator.aspx> fill in the blank weight and length growth evaluation—percentile determination growth chart for infants.
8. Centers for Disease Control and Prevention Growth Charts  
[www.cdc.gov/growthcharts/](http://www.cdc.gov/growthcharts/)
9. Breast milk endures as the ideal source of nutrition. Study demonstrated Human milk of mothers of pre-term infants has higher concentrations of immunoglobulin A—sustained over longer periods of time than does the human milk of mothers of term infants.
10. Formula-fed premature infants receiving transitional formula do not require additional multivit's. They do require vitamin D supplements by 2 months of age until they've transitioned to milk or a formula containing vitamin D.
11. Soy formulas are not recommended for pre-term infants because of the low phosphorus content. Premie infants receiving standard term formula (20 kcal/oz) require multivit's until reach 3.5 kg or are taking more than 750ml per day.
12. Pre-term infants fed unfortified human milk should receive 2 to 4mg/kg/ per day of an iron supplement.
13. Infection protection for human milk fed to premature infants extended through 7 months corrected age as evidenced by decreased incidence of lower respiratory infections.

14. Plot weight/height using both the

- a. 2000 Centers for Disease Control and Prevention (CDC) Growth Chart
- b. The 1999 Infant Health and Development Program Growth Percentiles for LBW and Very Low Birth
- c. Pre-term infants may not display the same feeding cues as term infants, and parents should be taught to look for alertness and rooting. In the preterm infant, crying is a late sign of hunger.

iv. **Sleeping—encourage Mom to interact with baby b/4 feeding and then after feeding let sleep...sleep sleep sleep**

- a. Mom's may be confused because as a preemie infant let sleep on abdomen—putting on back is recommended by AAP—no side-lying position because infants will roll over onto their tummy from their sides
- b. Make child feel snuggled up by rolling thin blankets and place around sides, bottom, and even touching top of head.
- c. While baby is awake—put on abdomen to encourage use of neck and shoulder muscles

v. **Safety**

1. AAP recommends that infants at risk of respiratory problems be formally tested in a car seat b/4 transport home. Travel for infants at risk of respiratory compromise should be minimized, and infants who cannot tolerate a semi-upright position should use a prone or supine safety device

vi. **Immunizations**

1. Routine vaccination should proceed according to chronologic age with minor exceptions Preterm children immunized at the recommended chronological ages displayed antibody responses similar to those for full-term children for most immunizing antigens.
2. In study looking at hospitalization rates for acute respiratory illness in children younger than 1 year of age, 15 to 40 children per 1000 were admitted to the hospital for RSV. 81% of hospitalization for bronchiolitis occur during

months of November through March, with RSV determined to be the primary causative agent for admission.

3. Premature infants determined to be at risk when discharged from NICU during months of October-November through March-April in the US receive RSV prophylaxis with parental consent prior to discharge (AAP, 2003)
  - a. RSV recommended for infants < 24 months of age with chronic lung disease, significant cardiac problems, < 6 months at age at start of RSV season, born < 32 weeks' gestation—and who have multiple risk factors such as tobacco exposure, school-aged siblings, exposure to environmental air pollutants, etc. (AAP, 2003)
4. Premature infants starting at 6 months chronologic age should receive vaccination from influenza (AAP, 2003).
  - a. Require two doses during first year to produce satisfactory antibody response
  - b. Vaccination of household members imperative.
- vii. **Early intervention-** Each well-child examination should include developmental surveillance so that early intervention can be initiated if a developmental delay is diagnosed.
  1. **Locally available early intervention services for children up to 3 years of age guaranteed by law through the Individuals with Disabilities Education Act**—services from birth through 3 years.
  2. **Screening, evaluations, identification of service providers, coordination of service, etc)**
  3. **Motor scores of preterm infants should equal their full term peers by 2 to 3 years of age (Wilson and Craddock, 2004)**
  4. **Preterm infants of higher birth weight are more likely to approximate their peers than are VLBW children (Wilson and Craddock, 2004)**
- viii. Physicians should provide families with an accurate and comprehensive summary of the neonatal course with specific written instructions for all necessary follow-up. All well-child encounters require developmental screening to identify children at risk.

## **XVIII. Outcomes Research**

- a. Study following infants born at age of 25 or fewer weeks in gestation assessing them at two and a half and six years of age. Of the 302 surviving babies available for follow-up, 50% had no disabilities, 25% had some level of disability and 25% had severe disability.

Investigators followed 241 of the surviving children at early school age and assessed them at an average age of six years and four months....There was a high rate of disability in the group—learning disabilities being more accurately measured than at earlier assessment. 20% of children had no problems, while 22 percent had severe disability such as CP, blindness, deafness, low cognitive scores.

- b. Boys have greater risk of severe disability and lower scores for cognitive brain function than girls, supporting concept that male sex is an important biological risk factor in extremely pre-term infants
- c. Preterm infants less likely than term peers to perform at grade level without supplemental therapies (Davis, Sweeney, et al, 2004)
- d. Preterm infants with two involved parents (not necessarily married) were three times more likely to perform at grade level than were their term peers (Davis, et. Al, 2004)
- e. Larger-scale folds across the bottom of the brain surface develop the fastest in premature (born more than seven weeks early) infants (top of brain), while medium-scale folds develop the fastest in older premature infants, born between seven and two weeks early (middle). In older infants and children, fine folds develop the most quickly across the brain surface (bottom). Their resulting model of cortical development may serve as a biomarker, or biological indicator, for early diagnosis of neurological disorders such as autism.
- f. Children born about 3 months prematurely are 3 to 4 times more likely to struggle in school than children born full term. (Univ of Buffalo, 2000)
- g. Almost ½ of children who survive extremely preterm birth have neurologic and developmental disabilities (Yale University, 2000)
- h. Brain scans of children born prematurely show key areas of the brain are much smaller than those of children born at full term. Differences in brain volume on average were

reduced from 11 to 35% compared to full term babies. Those born at younger gestational ages most affected (Yale, 2000)

- i. Incidence of major developmental disabilities is much higher in infants less than 1,000 grams at birth. Study demonstrated that when brains develop prematurely outside of the womb they are vulnerable to developmental disturbances (JAMA, 2000)
- j. Study conducted by British researchers showed that 52% of preemies had problems at age 2 ½ though many other prematurity related problems did not show up until age 5 (New England Journal of Medicine, 2000).
- k. Children weighing 2 lbs or less at birth experienced significant learning disabilities persisting into their teenage years (New England Journal of Medicine, 2000)
- l. Conventional medical wisdom, based on previous studies, has determined that premature children who were not seriously physically disabled would catch up to other youngsters by age 5, but new research indicates that academic and behavioral problems often surface by school age
- m. Premature children have higher levels of anxiety, and lower self-concept—the premature children were found to have more disturbances at home and school. The smaller the birth weight, the less emotionally adjusted the child will be (Journal of Clinical Psychology, 2006).
- n. Risk for learning disabilities increases as weight at time of birth decreases. Long-term follow-up (to age 18 y.o. and 19 y.o of boys whose birthweight less than 1500 grams—had more visual and hearing impairments and were at much higher risk of CP and other signs of mental impairment as evidenced by lower intelligence test scores and shorter schooling.
- o. Very low birthweight babies performed more poorly than higher birthweight babies on tests of math, language, perceptual motor and attentional skills
- p. Low birth weight children had lower school performance and IQ scores at age 13 than normal birth weight children irrespective of parental socio-economic status.
- q. Extremely low birthweight infants (less than 800g) showed significant increases in distractibility, activity levels, anxiety, and withdrawal at school age compared to children who were not born premature. Conclusion: Stress is a factor in outcomes—but what outcomes still unknown...When developmentally supportive and family centered care becomes standard practice in NICU's and post-discharge the neurobiological impact of chronic stress and trauma can be reduced.

- r. 155 infants, classified by perinatal morbidity and birth weight, was assessed during a home visit. Neonatal illness, socioeconomic status, preschool health, and motor predictors explained 44% of the variance in functional performance. Functional performance, a child's ability to perform the tasks of daily living and to fulfill expected social roles. (Sullivan and Msall, 2007). Conclusions: Birth weight and perinatal morbidity continue to exert an effect 4 years later on functional performance, health status, and motor outcomes.
- s. VLBW, less than 1500 g at age 12 show significantly greater risk of ADHD, generalized anxiety and symptoms of depression. A met-analysis carried out by Bhutta, et al demonstrated that 81% of studies done on cognitive and behavioral outcomes of school-aged preterm infants indicated increases in internalizing and externalizing behaviors and more than twice the risk of developing ADHD.

### **XIX. Medical Homes in Minnesota**

- a. Minnesota's Medical Home Learning Collaborative is now starting its 3<sup>rd</sup> year of operation.
- b. Concept of Medical Home: A model for caring for children with special needs in which primary care provider's role is to make sure patient's care is coordinated and effective. Kids with special health needs account for 80% of pediatric health care expenses.
- c. In MN, approximately 160,000 children younger than 18 years have special health care needs. A disproportionate number of children are on publicly supported programs through Medicaid or the State Children's Health Insurance program. Their care is much more costly than that of their same-age peers.
- d. Goal is to create a more effective type of primary care for children with special needs—provider is primarily making sure patient's care is coordinated and effective. In the end—better health outcomes and better quality of life.

#### Clinics Involved

Alexandria Clinic	South Lake Pediatrics, Eden Prairie
Brainerd Medical Center	
CentraCare Women and Children's clinic St. Cloud	
Grand Itasca Clinic and Hospital, Grand Rapids	
Lakeview Clinic, Watertown	
Mankato Clinic, Mankato	
New Ulm Medical Center, New Ulm	

North Point, Mpls  
 Owatonna Clinic, Owatonna  
 Park Nicollet, Plymouth  
 Regina Medical Group: Cottage Grove and Hastings  
 Cass Lake Indian Health Service  
 Health Partners White Bear Lake  
 Hennepin County Medical Center  
 Olmstead Medical Center, Rochester

### On-line resources

<http://www.preemiecare.org/Glossary.pdf> This website contains 191 acronyms and terms and provides additional links to information. A must see website.

<http://www.ttmf.org/glossary.html> An easy to read alphabetized definition of terms—useful for reading physician discharge summaries and other health care provider generated documents

<http://www.coburnkids.com/preemie-glossary/> This set of NICU terms was written by the parents of an infant requiring care in the NICU.

<http://www.prematurebaby.ie/glossary.php> a more limited list of terms with definitions but printable and able to be used quickly

[http://www.texaschildrenspediatrics.org/healthlibrary/pa\\_premie\\_hhg.aspx](http://www.texaschildrenspediatrics.org/healthlibrary/pa_premie_hhg.aspx) a great site for parents

<http://www.health.state.mn.us/divs/fh/mcshn/mcshn.html> Minnesota Title V MCH Fact Sheets

<http://www.health.state.mn.us/divs/fh/mcshn/discond.htm> Minnesota Title V Fact Sheets

\*complete reference list provided at time of conference