

ANEMIA - The condition of too few red blood cells.

AGENESIS - absence.

AGENESIS OF THE DIAPHRAGM - complete absence of the diaphragm.

ANALGESIC - (pain killer) medication that relieves pain and discomfort (Tylenol, Acetaminophen, Aspirin, Morphine, Fentanyl, etc.).

ANTIBIOTICS - Drugs that can either kill bacteria or slow their growth; used in treating bacterial infections.

APNEA - The condition of not breathing.

ASPIRATION - Inhalation of material (formula, meconium or stomach juice) into the trachea (windpipe) and lungs.

ABG - (Arterial Blood Gas) a blood gas drawn from an artery; usually from the patient's arm, leg, or central line.

ARTERY - a blood vessel that carries oxygenated blood from the heart to the body's organs.

BAGGING - a procedure that uses a Respiratory (e.g., Ambu) Bag to manually pump air into a patient's lungs.

BILIRUBIN - A pigment produced in the breakdown of red blood cells that appears as yellow skin coloring (jaundice).

BILIGHTS - Lights placed over or under the infant to help in the breakdown of bilirubin, thereby reducing jaundice.

BLOOD GASES - Laboratory test to determine the amount of acid, oxygen and carbon dioxide in the blood.

BLOOD SATURATION - the percentage of oxygen bound to hemoglobin in the patient's blood. For a healthy person, a normal value is close to 100%.

BLOOD TRANSFUSION - carefully screened blood given to a patient to replace blood lost during a surgical procedure.

BOCHDALEK HERNIA - (Foramen of Bochdalek) an opening through the left diaphragm between the chest cavity and abdominal cavity toward the back of the body. It is the most common form of diaphragmatic hernia.

BRADYCARDIA - Slow heart rate.

CAPILLARY - a blood vessel that carries blood between the smallest arteries and the smallest veins.

CAT (or CT) SCAN - A special X-ray study which uses a computer to create an image of the body or a part of the body.

CARBON DIOXIDE - gas exhaled by the lungs after oxygen is absorbed. Insufficient exchange of oxygen and carbon dioxide can cause serious problems for the patient.

CBG- (Capillary Blood Gas) a blood gas drawn from a capillary blood vessel; usually from the patient's toe or finger.

cc- liquid measurement (30cc = 1 ounce).

CENTRAL LINE - a more permanent type of I.V., surgically placed in an artery or vein.

CHEST P.T. - Vibration on the chest (Physio-Therapy) to loosen secretions and suctioning to remove mucous from the lungs.

CHEST TUBE - a drainage tube surgically placed in the patient's chest and connected to a suctioning device to prevent fluid from collecting in the chest cavity.

CHRONIC - any long-term medical problem.

CPAP- Continuous Positive Airway Pressure which helps a patient to maintain the necessary pressure needed to keep his/her lungs inflated.

CYANOSIS - Condition in which the skin, lips and nails are blue from lack of oxygen in the blood.

DEXTOSTIX - A special strip of plastic used to determine how much sugar is present in a sample of blood.

DISTENDED ABDOMEN - Full, tight appearance of the stomach.

DIURETICS - medications that increase the amount of urination; used to avoid or decrease large amounts of fluid build-up or edema; patients may need extra potassium chloride while on diuretics (Edecrine, Diuril, Lasix, Spirolactone, Hydrochlorothiazide etc.)

EDEMA - swelling

EEG (Electroencephalogram) - Test done to measure brain wave pattern or to look for seizures.

ECHO (Echocardiogram) - A heart test done with ultrasound waves to pick up the image of the heart and its vessels through the chest wall without hurting the baby.

ECMO (Extracorporeal Membrane Oxygenation) – a heart-lung by-pass machine that takes over the work of the patient's heart and lungs. A very large catheter, a plastic tube, is placed in an artery or vein in the

patient's neck. Blood is then removed from the patient's body, oxygenated, and returned to the patient.

EPINEPHRINE - a medication that can be used to restore cardiac rhythm during cardiac arrest.

ENDOTRACHEAL TUBE (E.T. Tube) - a tube placed through the patient's nose or mouth into the trachea to help provide mechanical or manual ventilation.

FELLOW - a doctor training to become a specialist in a given field of medicine.

FEMORAL ARTERIAL LINE - a central line placed in an artery near the patient's groin.

FOLEY CATHETER - a plastic tube inserted into a patient's urethra to aid in urination and taking "clean" urine cultures.

GAVAGE - A method of feeding the baby fluids by inserting a small plastic tube, called an orogastric (OG) tube, through the mouth or nose into the stomach.

GASTROINTESTINAL REFLUX - an illness that occurs when the stomach contents "backup" into the esophagus, where they can possibly be aspirated (inhaled) into the lungs.

GESTATIONAL AGE - Age of the baby in weeks, determined from the time of conception.

GLUCOSE - Sugar in the blood used for energy.

GRUNTING - Noises heard when a baby is having difficulty breathing.

HEEL STICK - A small prick in the heel to obtain a blood sample.

HEMATOCRIT - The percentage of red blood cells in the blood.

HYALINE MEMBRANE DISEASE (RDS) - A respiratory disease often seen in premature infants caused by immature lung development.

HYPERALIMENTATION - Giving nutrients through a vein for babies who cannot be fed by mouth.

INCUBATOR (Isolette) - An enclosed, heated Plexiglas bed.

INTRALIPID - A white, high calorie solution also administered through a vein to provide fat for babies who cannot be fed by mouth.

INTRAVENOUS (IV) - Introduction of fluids into a vein.

INTUBATION - Insertion of a tube through the nose or mouth into the trachea (windpipe).

I & O (Intake and Output) - Total amount of fluid taken in, then lost as urine, stool or perspiration.

JAUNDICE - (See bilirubin)

LUNG HYPOPLASIA - failure of one or both lungs to develop fully.

MECONIUM - A baby's first stool, which is greenish or black.

MORGAGNI HERNIA (Foramen of Morgagni) - diaphragmatic hernia occurring near the front of the body, near the breastbone.

NASAL CANULA - A special tubing that is used to give oxygen through the nose, making holding and feeding easier.

NARCOTICS - medications that cause the patient to sleep; highly addictive and must be weaned slowly (Fentanyl, Methadone, Codeine, Morphine, etc.)

NITRIC OXIDE - a gas that is used as an inhalant in order to try to enhance lung growth and recovery

NPO - Baby will get nothing to eat by mouth.

NISSEN FUNDOPLICATION - a surgical procedure where the opening between the lower end of the esophagus and the top part of the stomach is narrowed to prevent stomach contents from flowing backward into the esophagus.

NG-TUBE (Nasogastric Tube) -a plastic tube inserted through the patient's nose into the patient's stomach or intestines to aid in digestion when the patient cannot eat by mouth.

PAVULON - a medication that temporarily paralyzes the patient's muscles to keep him/her still when their condition can be threatened by movement (as when on ECMO).

PICC (pick) LINE - A special IV line used to provide fluids into a vein. In general, a PICC line is very stable and lasts longer than a typical IV.

PNEUMONIA - Inflammation or infection of the lungs.

PNEUMOTHORAX - Accumulation of air between the outer lining of the lung and the chest wall, causing collapse of the lung.

PREMATURE INFANT - A baby who is born before 37 weeks of gestation.

PULSE-OXIMETER - a machine that reads the patient's heart rate and blood saturation levels through a probe taped to the patient's toe or finger. ("ET" Lights)

PULMONARY HYPERTENSION - High blood pressure in the pulmonary artery that conveys blood from the right ventricle to the lungs. The pressure in the pulmonary artery is normally low compared to that in the aorta.

RESPIRATOR (Ventilator) - A machine that breathes for an infant.

ROUNDS - The gathering of doctors, nurses and other health care professionals to discuss the condition and care of patients.

SEDATIVE - a medication that calms and/or puts the patient to sleep so that he/she will not feel pain or discomfort (Versed, Ativan, Valium, Chloral Hydrate, etc.)

SEPSIS - Infection.

SPINAL TAP (LP) - Insertion of a small needle through the back into the spinal column to obtain a sample of spinal fluid.

STEP DOWN - Decreasing in stages, in the amount of care required.

STOOL - Bowel movement.

SUCTION - Removal of secretions from the nose or throat or from an endotracheal tube using a small plastic tube connected to a vacuum outlet.

TPN AND LIPIDS - high calorie I.V. fluids used for long-term nutrition.

TRANSFUSION - Giving blood or blood products to a baby through a vein.

UMBILICAL CATHETER (or Umbilical Line) - A tiny plastic tube inserted into the blood vessel of a baby's umbilical cord used to give the baby fluids and to withdraw blood samples.

VITAL SIGNS - Temperature, heart rate, respiratory rate and blood pressure.

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MISSION STATEMENT:

Breath of Hope exists to raise awareness of congenital diaphragmatic hernia by working with parents, family members, and medical professionals to educate and support all who are affected by or want to learn more about CDH.

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THIS DOCUMENT ALWAYS IN REVIEW