



**Arkansas
Children's
Hospital**

Dear Parent,

Your child has been placed on ECMO life support in one of the Intensive Care Units at Arkansas Children's Hospital. We understand this can be a very stressful time for parents and family members, and our team is here to assist you through this time. The ECMO staff wants to help address any concerns you may have about the care of your child while on ECMO. This guide is designed to help answer some of your questions and provide basic information relating to ECMO.

ECMO is performed within the Neonatal Intensive Care Unit (NICU), Pediatric Intensive Care Unit (PICU), or the Cardiovascular Intensive Care Unit (CVICU) of Arkansas Children's Hospital. Each of these units consists of specially trained staff members such as the Physicians, Nurse Practitioners, Nurses, Pharmacists, Respiratory Therapists, and many others. In addition to these members, a trained ECMO specialist, an assistant ECMO coordinator, and the director of ECMO services will provide support and care for your child.

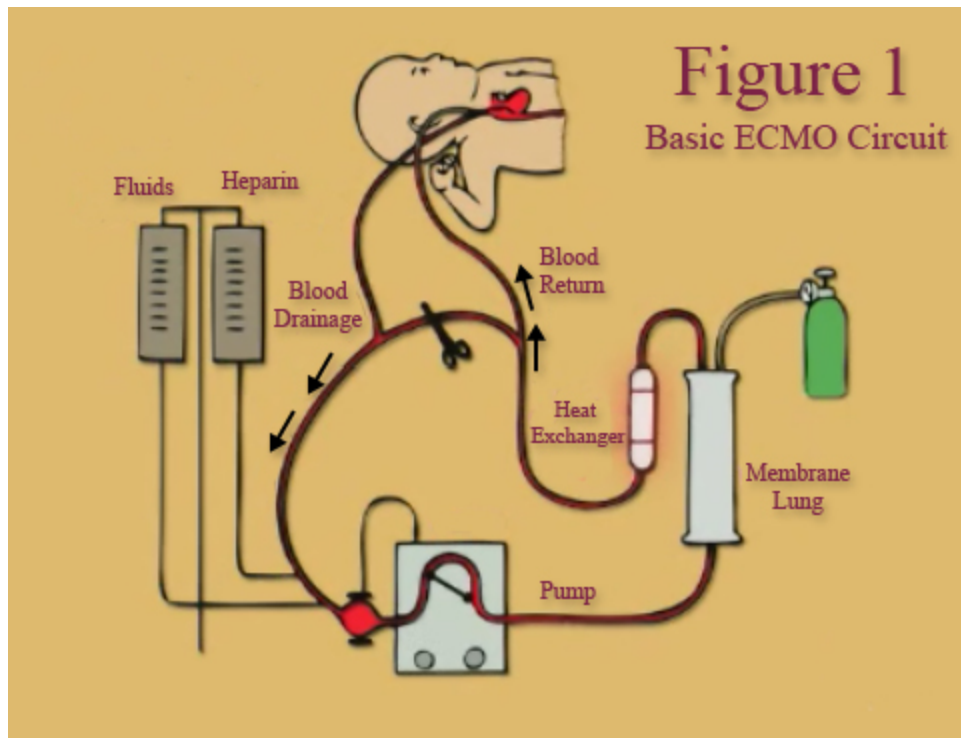
Each of the intensive care units has a parent handbook to orientate you to their specific areas and visitation guidelines. They contain explanations to unit policies as well as information regarding dining, chapel, and laundry facilities. Arkansas Children's Hospital has a Family Centered Care Philosophy because we believe that you play an important role in your child's recovery. We embrace open communication so that families understand all aspects of the care provided to your child. Your child is a precious gift and we thank you for letting us be a part of their care.

Sincerely,

The Arkansas Children's Hospital ECMO Team

What is ECMO?

ECMO (Extracorporeal Membrane Oxygenation) is a method for temporarily supporting patients with severe heart and/or lung failure. The ECMO circuit essentially adds oxygen to the blood and can help the heart pump blood to the body. Basically, it is similar to a heart-lung bypass machine used during open heart surgery but can be used for a longer treatment period. ECMO uses an artificial lung called a membrane. Blood is pumped through this lung by the machine where carbon dioxide is removed and oxygen is added. This enables the patient's doctors to use lower settings on the ventilator (breathing machine), hopefully allowing the patient's lungs to "rest" and heal. Since blood is circulated outside the body (extracorporeal) and loses heat, the oxygenated blood passes through a heat exchanger warming it prior to returning to the patient. The ECMO pump can provide cardiac support by taking over part of the heart's workload. In time, the reduced effort by the heart may improve its function (See Figure 1).



When is ECMO used?

ECMO is an option for those patients who have acute, life-threatening failure of the heart and/or lungs that is 1) not responding to other types of support and 2) felt by the patient's physicians to likely be reversible (i.e. treatable). In cases of severe lung problems, ECMO would be considered when the lungs are so injured and sick that mechanical ventilators (breathing machines) are either failing or have such high settings that they may cause the lungs further harm or damage. ECMO functions as the patient's lungs until the lungs have hopefully healed enough for the ventilator to again provide adequate support for the patient. ECMO does not replace treatments such as antibiotics or medications that help to remove edema/fluid from the lungs. The sole purpose of ECMO is to "buy time" for the patient's lungs to heal from whatever disease process got them sick in the first place.

Likewise, ECMO can be used to help a failing heart provide enough blood flow to the body to support vital organ function. This may sometimes be necessary either before or after heart surgery, or in cases of disease that seriously weaken the heart muscle's ability to pump blood. Sometimes a patient's heart is so weak that a heart transplant must be considered. If that is the case, ECMO may be used to help pump blood to the patient's vital organs until a transplanted heart is obtained. This is called a "bridge" to a transplant. ECMO provides ample blood flow and oxygen to major organs like brain, liver, and kidneys helping them to maintain function during the child's illness. At Arkansas Children's Hospital, ECMO has been successfully used for conditions such as:

- Severe Pneumonia
- Meconium Aspiration Syndrome (MAS)
- Pulmonary Hypertension (PPHN)
- Congenital Diaphragmatic Hernia (CDH)
- Life-threatening Asthma Attacks

- Septic Shock
- Bridge to Heart Transplant
- Supportive Treatment Before Cardiac Surgery
- Supportive Treatment After Cardiac Surgery
- Sudden Cardiac Arrest

How will ECMO be managed?

Every child on ECMO at ACH has a large team taking care of him/her from beginning to end. This ECMO team is made up of the surgeon, specialized doctors, ECMO specialists, nurses, respiratory therapists, social work, chaplains and any other members of the ACH team that might be involved with direct care. Initially, the surgical and ECMO teams will be called by the patient's doctor, usually a pediatric intensivist, pediatric cardiologist, or a neonatologist, to place the child on ECMO. The surgeon will place a tube or tubes into the large blood vessels in the neck or the tubes may come out of the chest if the patient has just had heart surgery. The tubes are then connected to the ECMO circuit. The patient's blood drains into the circuit and is circulated up through the artificial lung, where it receives oxygen before returning back to the patient.

There are two types of ECMO support depending on the patient's medical condition. Veno-arterial ECMO (VA ECMO) is used when the patient requires assistance for both the heart and the lungs. The blood is drained from a very large vein and once oxygenated returned through a large artery. This process takes most of the workload off both the child's heart and the child's lungs, providing support to vital organs and tissue. Veno-venous ECMO (VV ECMO) is used primarily when the lungs have failed but the heart is still working fairly well. The blood is drained from a large vein and is returned with oxygen through the same vein. Both types of ECMO provide efficient oxygenated blood to organs and the body tissues.

During ECMO when efficient flow is established to your child the ventilator will be adjusted to settings that allow the lungs to rest. The breathing machine settings remain at rest until your child is ready to come off ECMO. The lungs and/or heart may take days to weeks to heal and this time varies based upon the child's illness. As your child improves, the ECMO flow will be turned down (weaned) and the lungs and/or heart will do more of the work.

Your child will be continuously monitored on ECMO while in the intensive care area. Labs will be drawn often to help manage the ECMO pump and your child's medical treatments. X-rays will be done daily to review lung condition. For baby's, an ultrasound of the head will be done regularly to check for bleeding that can occur in the head. Transfusions of blood products are required to keep your child's blood counts normal. These products are given routinely to assist your child with clotting and to help oxygenate. As before ECMO, your child will continue to receive regular nursing care. Your child will be receiving a drug called heparin which helps to prevent clotting in the ECMO circuit. The ECMO specialists will do regular ACT (activated clotting time) checks to adjust the heparin dose.

Will my child hurt?

Your child's comfort is important to you and a priority to us. Before ECMO is initiated your child will receive medication to prevent pain and to help them rest during the procedure. Once on ECMO, your child will receive medication to relax and prevent pain continuously and may receive additional doses of medication at times to help them relax. Family involvement is important because you know your child best. We will need your assistance to improve your child's comfort and in doing so assist your child to heal. Here are some of the things you can do:

- Allow your child periods to rest by decreasing noise, activity, and the number of visitors to the bedside.

- Bring your child's favorite music that may help to relax and comfort them.
- Comfort your child with a calm voice or touch.
- Leave a tape of you and or your family's voice to play for your child.
- Assist with care when the nursing staff feels it's safe for you child.

What risks are there with ECMO?

There are risks or complications that can occur while your child is on ECMO. The greatest of these risks is bleeding because your child will be getting a drug called Heparin. Heparin plays an important role in that it reduces the formation of clotting within the ECMO circuit. However, it reduces the patient's ability to clot and causes increased risks for bleeding at surgical sites, internal bleeding, and an increase for bleeding in the brain. The newborns and young baby's may have occasional head ultrasounds to assess for bleeding. Labs are run frequently to carefully adjust the amount of heparin used and to monitor other blood products that assist in clotting. Small blood clots or emboli pose an additional risk and can be introduced into the patient's blood stream from the circuit.

The circuit has many moving parts that work together to provide support for your child and mechanical failure can occur. These failures are extremely rare; however, the risks for blood loss and the introduction of air to the patient can cause damage to organs, the brain, and even death. The circuit is monitored frequently by a highly trained specialist who will respond to any and all emergencies that may arise.

There are additional risks such as those associated with the transfusion of blood products. There are increased risks for infection related to the direct contact of the ECMO circuit with the patient's blood stream. There may be associated risks with patient transport for procedures such as cardiac lab, surgery, CT scan, or any other major movement required for patient care.

When will my child come off ECMO?

There are two reasons the doctors will take a patient off ECMO 1) the patient has made improvement and does not require support for the heart and/or lungs from the ECMO circuit or 2) the patient's condition has become worse and the patient's condition is no longer reversible (i.e. treatable). Many patients' conditions improve from their "rest" on ECMO and are able to be weaned or slowly turned down on ECMO to the point that a surgeon can take them off the device. These patients have improved enough to come off ECMO but may still require many forms of traditional treatment such as breathing machines and medications to support them. They have progressed from an extreme life saving tool but will continue to require the intensive care management. If a patient's condition is becoming worse and/or the removal of ECMO is related to a complication the doctors treating the child will speak with you concerning your options. The reason ECMO is utilized is because traditional means of support were not able to provide recovery. Additionally, ECMO is not always able to provide a means of recovery for all patients. Here at Arkansas Children's Hospital we strive hard for our patients and their families from beginning to end to provide care, love, and hope to all.

ECMO Glossary of Terms

ACT (Activated Clotting Time): a test to measure how long it takes for blood to form a clot.

Antibiotic: a medication given to treat bacterial infections.

Arterial Cannula: a large tube the surgeon placed into a blood vessel in the neck or chest.

Blood Gas: is a sample of blood taken from an artery or vein that tells how well your child is receiving oxygen. The sample is taken from an artery (ABG), from a vein (VBG), or from a capillary (CBG).

Bridge to Transplant: when ECMO is used to help pump the patient's blood to vital organs until a suitable heart transplant can be obtained.

CAT Scan (CT): a diagnostic test using x-rays to make a three dimensional image of the inside of the body such as organs. This test is performed to give the doctors more detail to provide better medical information.

Cannulas: tubes placed into blood vessels in the neck or chest by a surgeon that provide flow for the ECMO circuit.

Chest Tube: a tube that is placed in a space next to the lungs to help drain air or fluid.

Chest X-ray: a diagnostic test using x-rays to give the doctors a radiographic picture of the patient's lungs, heart, and other chest structures. These are performed daily in ECMO to assess cannula placement, chest tube placement, and lung condition.

Congenital Diaphragmatic Hernia (CDH): a life threatening medical condition that is present at birth characterized by a hole in the diaphragm or tissue that separates the lungs from the abdominal organs. The hole allows for abdominal organs to occupy the space that the lungs would normally grow in. Therefore, the lung(s) never develop to their normal size and do not function normally at birth.

Congenital Heart Defect (CHD): a medical condition, possibly life-threatening, which is present at birth and is characterized by an abnormal heart and/or heart vessels. The condition usually upsets the normal flow of blood in or out of the heart. These changes can cause the heart to work hard and less efficiently.

Decannulate: to remove the tubes from the blood vessels. This is performed by the surgeon when a patient is taken off ECMO. However, this can occur as an emergent complication while on ECMO during transport, a procedure, or anything requiring the movement of the patient while on ECMO. Accidental decannulation is an extremely rare occurrence at ACH as our patient transports both mobile and within the hospital for tests and procedures is exceptional.

ECHO: a medical imaging tool using ultrasound to assess the function of the heart.

ECMO: is a technique of providing both heart and lung support outside the body with a heart/lung bypass machine. It provides oxygen to patients whose heart and lungs are so severely diseased that they can no longer serve their function.

ECMO Flow: The amount of blood flowing through the ECMO circuit per minute.

ECMO Pump: The machine that controls how much support the patient's heart/lungs is receiving. It can act as an artificial heart for the patient and pumps the blood through the oxygenator membrane back to the patient.

ECMO Team: the team that is composed of specially-trained Physicians, Registered Nurses, and Registered Respiratory Therapists.

Electroencephalogram (EEG): a diagnostic test given to record brain activity using small electrode placed on the patient's scalp. This test provides information on the brain activity normal or abnormal and can provide information concerning seizure activity.

Edema: is the swelling that can occur in any tissue or organ due to the excessive buildup or increase in fluid.

Head Ultrasound: is a medical imaging tool using ultrasound to assess the head for bleeding and edema.

Heat Exchanger: a device used to warm the blood in the ECMO circuit before it returns to the patient.

Hemofiltration: is where blood is passed through a set of tubing (a *filtration circuit*) via the ECMO circuit to a membrane (the *filter*) where waste products and water are removed.

Intraventricular Hemorrhage (IVH): is bleeding in the brain common in infants, especially premature infants or those of very low birth weight, thought to result from changes in circulation to structures that are present in the growing brain. The lack of blood flow causes the death of brain cells and the breakdown of the blood vessels of those cells which leads to bleeding. This bleeding is itself a marker for injury that has already occurred however continuous bleeding can result in further injury to the brain.

ECMO can increase the risks for bleeding because the patient receives Heparin an anti-clotting medication and an IVH maybe a reason for discontinuing ECMO support.

Life Threatening Asthma: is a disease of the lungs in which the airway sometimes constricts, becomes inflamed, and may have large amounts of fluid or mucus, often in as a result to one or more triggers. In life threatening asthma traditional means of treatment may not successfully manage the illness and ECMO can assist to “rest” the lungs.

Meconium Aspiration (MAS): occurs when infants take meconium or stool into their lungs during or before delivery. This stool is sterile or germ-free but can cause serious problems for a newborn’s lungs. ECMO can be utilized to “rest” the lungs until they regain their ability to provide oxygen to the infant.

Magnetic Resonance Imaging (MRI): a diagnostic tool used to see the inside structures of the body. This type of imaging is usually completed after a patient has been on ECMO as a follow-up procedure.

Membrane or Oxygenator: an artificial lung that adds oxygen to the patient’s blood on ECMO and removes carbon dioxide.

Persistent Pulmonary Hypertension of the Newborn (PPHN): a disease process in newborns where the blood pressure in the newborns lungs remains high and does not permit the regular flow of blood into the lungs to be oxygenated but rather mixes with blood flow to the body. The mixing occurs in the heart and/or through a blood vessel that should have closed shortly after birth called the ductus. The blood then supplied to the body is lacking oxygen.

Pneumonia: is a disease of the lungs in which the small air-filled sacs of the lung responsible for taking up oxygen are irritated and flooded with edema.

Platelets: are some of the basic mechanisms in the blood used for the formation of clots. Platelets are regularly monitored and replace in ECMO as the circuit consumes some of them from the circulating blood.

Respiratory Distress/Failure: is a medical term for the inability of the lungs to exchange oxygen and/or carbon dioxide. Respiratory failure can be shown by observing a drop in oxygen in the blood (hypoxia) and/or a rise in carbon dioxide (hypercapnia). The patient's physician can observe these things from a blood gas level.

Septic Shock: is a life threatening medical condition caused by infection and sepsis (overwhelming bloodstream infection). Children are among the common victims as their immune systems cannot cope with the infection. The results of sepsis can be failure of the primary organs to work such as heart, lungs, kidneys, liver, and even death.

Sudden Cardiac Arrest: is the rapid stop of normal blood flow due to failure of the heart to beat well. Sudden arrest prevents delivery of oxygen to the whole body. Brain injury will probably occur if the sudden cardiac arrest is untreated for more than five minutes.

Ventilator: a machine that is attached to a tube in the patient's mouth or nose that delivers oxygen and removes carbon dioxide for patient's who cannot breathe on their own.

Venous-arterial (VA) ECMO: is a type of ECMO that provides support for the heart and lungs. One cannula is placed in a large vein and one cannula is placed in a large artery.

Veno-venous (VV) ECMO: is a type of ECMO that provides support for the lungs only. One cannula is placed in a large vein.

Weaning: is a process of slowly getting the child off ECMO, off a ventilator, or off medications as the patient's condition improves.