



ECMO PARENT MANUAL



Children's Mercy
KANSAS CITY



Dear Parents, Family and Friends:

Having a very sick child being treated in the environment of an intensive care unit is an extremely stressful situation. Knowing this, a group of critical care professionals have written this booklet to provide you with information, to answer some important questions you may have, and to help you cope with this difficult period.

The hospital staff will do their very best to take care of your child's medical needs. However, you, your family and friends will play an essential part in the care of your child. Your familiar face and voice are important in your child's care, and you will be encouraged to participate.

Feel free to ask questions or express concerns. There are many people to help you, including your child's bedside nurses, ECMO specialists, ECMO core team, ECMO director, perfusionists and physicians. All these medical people are familiar with the special questions and concerns of families of critically ill children.





Why Does My Child Need ECMO?

Your child is having difficulties getting oxygen to their body because their lungs or heart are not working adequately. Most children with severe lung or heart disease who cannot get enough oxygen into their blood by themselves can be helped with a breathing machine (ventilator) and medications given through an IV. However, if your child worsens despite these treatments, a therapy called **ECMO (Extracorporeal Membrane Oxygenation)** is available. This therapy allows the heart and lungs to rest and heal while the machine supplies needed oxygen to the blood. ECMO can also help ventilate or remove carbon dioxide from the blood. This same machine can act as an artificial heart to infants and children whose hearts are failing. Since 1975, more and more children every year who otherwise would have died have survived with ECMO.

What Is ECMO?

The ECMO machine is similar to a heart-lung machine used for open heart surgery. The surgeon places tubes (cannulas) into the large blood vessels, usually on the right side of the neck or in the groin depending on the size of your child. If your child has had heart surgery, the cannulas may be placed in the chest. From these cannulas, the blood is pumped by the ECMO machine through an artificial lung which adds oxygen and removes carbon dioxide. The blood then returns to the child. This cycle is repeated many times each minute. Once a child is on ECMO, the ventilator and heart medications can be turned down to allow their heart and lungs to rest and heal.

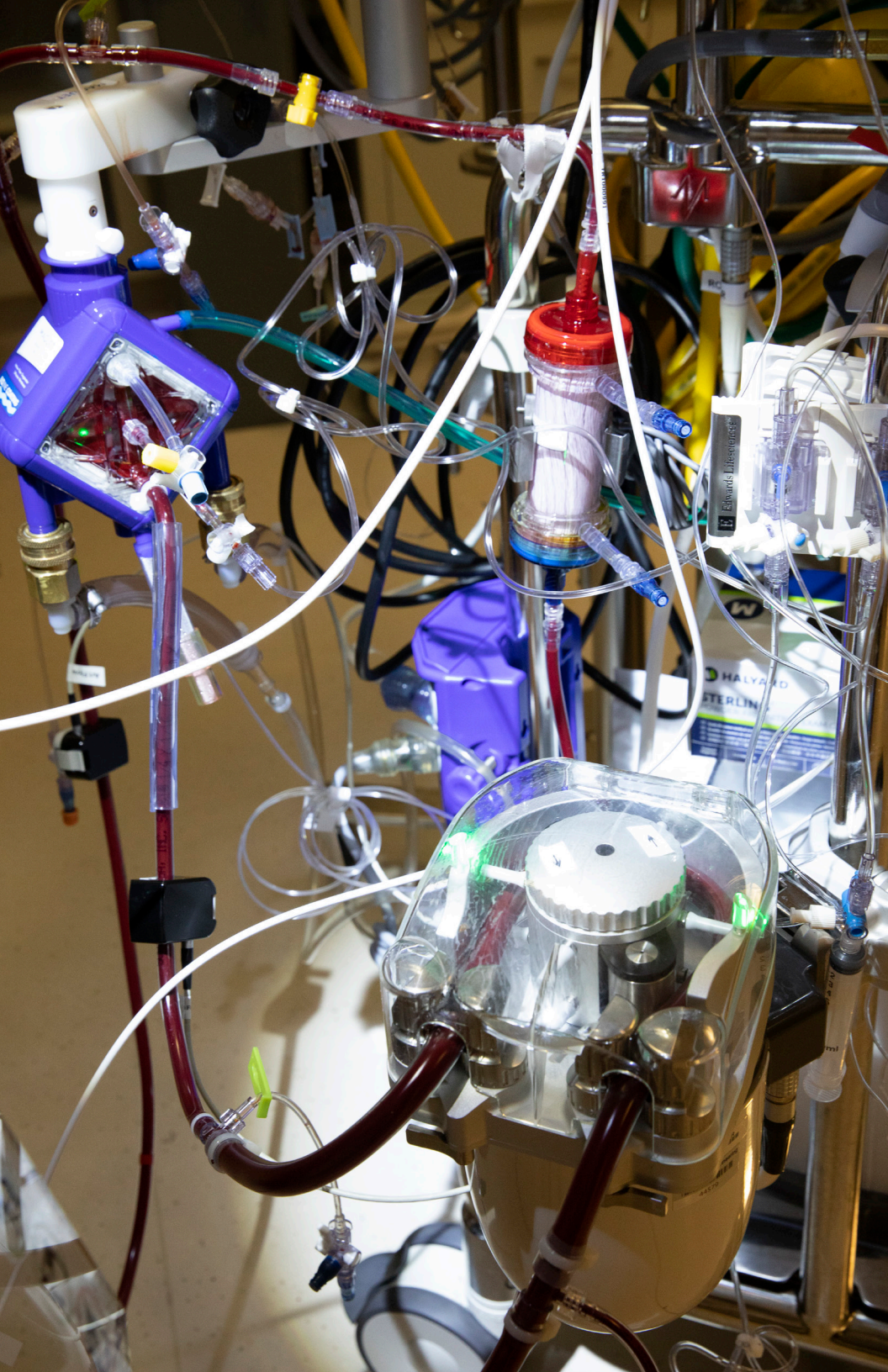
ECMO temporarily provides your child with the oxygen they need and removes carbon dioxide waste product until their heart or lung problems have healed. ECMO does not cure lung or heart disease; it merely supports your child and allows time for the lungs and heart to heal.

How Does ECMO Start?

Surgery must be done before ECMO can start to insert tubes (cannulas) that will take unoxygenated (blue) blood from your child's body to the artificial lung and back. This process is called cannulation and will usually be performed in the Intensive Care Unit at your child's bedside by pediatric surgeons.

During surgery, the major blood vessels, typically, the jugular vein and/or carotid artery, are stitched off at the time the cannulas are surgically inserted. Other blood vessels take over the job of carrying blood to and from your child's head.

Some children are placed on ECMO in the operating room when they are unable to be removed from the heart-lung bypass machine after open-heart surgery. These children may be placed on ECMO with cannulas inserted through the chest directly into the heart.



What Happens While My Child Is On ECMO?

Many children will be able to wake up and respond to your voice and touch. Some children will need to continue receiving sedative and paralyzing medicine while on ECMO and will not be able to respond. You may want to bring your child's favorite small toy, stuffed animal, blanket, or special music to put in the bed. Be assured, we will monitor your child's comfort closely and give pain medication as needed.

Even though your child will look much better when ECMO starts, it is important to remember that the ECMO machine is supporting them. ECMO does not cure heart or lung disease. The goal is that over the next several days to weeks, the lungs and/or heart should slowly heal.

While your child is on ECMO, we prevent the formation of blood clots by thinning the blood with an anti-clotting medicine. Because this medicine can increase the risk for bleeding, the ECMO specialist will frequently monitor the clotting process with a variety of lab tests. When ECMO is over, your child will no longer need the anti-clotting medicine, and the blood's natural clotting ability will return to normal in a few hours.

Platelets, the cells that help blood clot, are damaged easily in the ECMO machine and may fail to function properly. When this happens, we transfuse healthy platelets into your child's blood stream. Your child will probably receive frequent platelet transfusions, and other blood products, while on ECMO.



Many children prior to ECMO appear swollen and puffy. Their bodies may be unable to eliminate excess fluid (edema). Your child's hands, feet and face may be very swollen, as are their lungs. Extra fluid makes it harder for their lungs to heal. We treat this by giving medicines or by connecting a filter to the ECMO machine to pull extra fluid out of the blood and help your child's kidneys. The process does not necessarily mean their kidneys are not working; the filter only helps to decrease swelling faster.

To determine your child's progress, we draw small amounts of blood frequently for a test known as a blood gas. The blood gas measures the oxygen, carbon dioxide and acid levels in the blood. Increased oxygen levels in the blood over time show the lungs are improving and the amount of blood circulating through the ECMO machine can be decreased steadily. This increases the amount of blood circulating through your child's lungs so that they are doing more of the breathing work on their own. This process is called "weaning." The weaning process helps determine if your child is ready to be taken off the machine.

Other ways nurses and doctors can tell your child is improving:

- **Chest X-rays** - Every morning, X-rays of your child's chest are taken and evaluated.
- **Hyperoxia Test** - We may increase the oxygen level on the ventilator to 100 percent and obtain a blood gas with the morning labs. As the lungs improve, the oxygen levels in the blood gas increase. This test is only helpful in children who do not have congenital heart disease. If your child is on ECMO because their heart is not able to pump enough blood and oxygen to the body, this test will usually not be done.
- **Trial off ECMO** - We may perform a "trial off ECMO" to assure your child is ready to be removed from ECMO. This is a period of time (usually only a few hours) when your child remains attached to the machine, but the machine is not providing any support.



How Long Will My Child Be On ECMO?

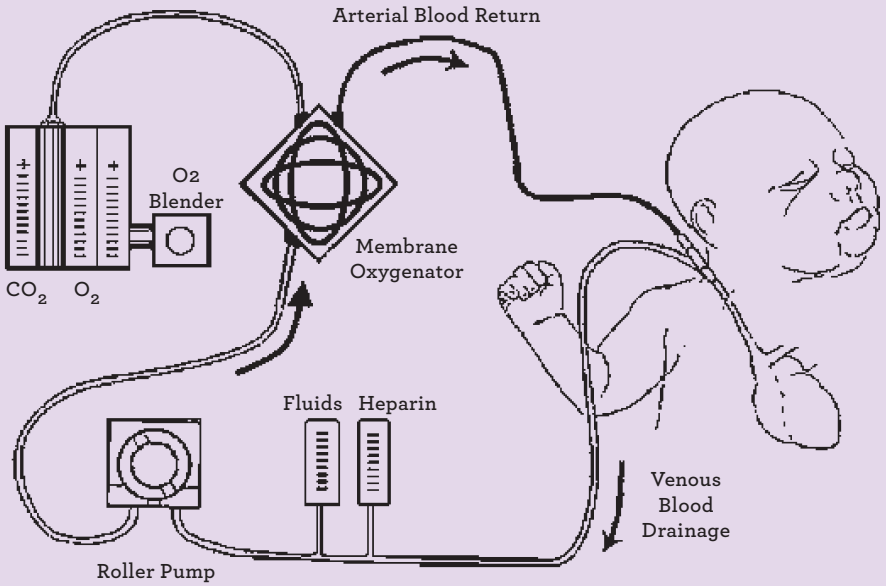
The length of time a child spends on ECMO varies. We consider the child's age, the type of lung or heart disease they have and any complications. The average time a newborn baby spends on ECMO is five to seven days. Some children may need to be treated with ECMO for a much longer time. If a child does not improve after several weeks, their lungs or heart may not be able to heal. If the disease cannot be reversed, and ECMO cannot help your child, your physicians will talk with you in detail about the situation. Remember that although ECMO may help your child's survival, it cannot guarantee it.

Once your child is ready to be removed from the ECMO machine, the surgeons must perform another operation to remove the cannulas (decannulation). This usually occurs at the bedside, although some children are taken to the operating room. You will be notified when decannulation is planned. You will need to be present in the hospital for the surgery unless other arrangements are made.



ECMO Circuit

This is a simple diagram of the ECMO circuit. The blood flows from one cannula into the ECMO circuit. The pump then pushes the blood through an artificial lung (membrane oxygenator) and then it returns to the child via the other cannula.



Questions And Answers

Will I be able to be with my child during ECMO?

Parents and families play an important part in a child's care and recovery. We strongly encourage visiting. The social workers will help you identify places to stay near the hospital overnight.

While your child is on ECMO, there are things you can do to help with their care.

- Provide special toys and other comfort items.
- Your voice and reassuring touch are important to your child. Studies show it may help children heal faster.
- Your child's nurse will be able to teach you to give comforting touch.
- You may be able to provide care such as changing diapers, helping with baths or other care tasks when appropriate.
- Make recordings of yourself reading stories or singing songs. Bring them in or send them in if you're not able to come yourself. When you're here, read a book to your child.
- Take care of yourself. Make sure you eat well and rest. Don't think you have to be by your child's side all the time. You are better able to participate in your child's care when you are rested and nourished.
- Let your family play a part. Siblings can draw or color pictures for display at the bedside. Or they may choose a small toy to send.
- Keep a journal of your child's progress. Referring to it when you speak to your child's doctors can help you better understand what is happening and also remind you of questions to ask.
- Our child life and musical therapy departments are also great resources for ideas.

Remember; when you are away from the bedside, you can call any time to check on your child. We are always happy to talk to you.

Is ECMO painful?

When the cannulas are surgically placed or removed, we will give your child pain medication and muscle relaxants so they do not feel any pain or move during the procedure. Children on ECMO usually receive sedation and pain medicine, but often are able to mildly wake up and respond. Some children will need to receive large doses of pain medicine and muscle relaxants the entire time on ECMO and will be unable to move or respond, especially when the ECMO cannulas are placed directly in the chest. Physical and occupational therapy may be beneficial for children who are stable enough. This may help decrease the risks of overall physical weakening.



What is the ECMO flow?

A certain amount of blood, measured in mls (milliliters) per minute, circulates through the ECMO machine every minute. This is the “flow” of blood through the ECMO circuit. When ECMO is begun, the flow will be high because the machine is oxygenating most of the blood. As your child improves, the flow through the ECMO machine decreases because their own lungs and heart share the work load.

What are the complications from being on ECMO?

Any child who needs ECMO therapy is very ill. Usually ECMO is the only chance these children have to survive. Using ECMO does involve some risks. That is why we will watch your child very closely.

Specific risks are:

- **Bleeding** - Your child's blood must be kept from clotting while it is going through the ECMO machine, so we give a medicine to prevent clotting. Sometimes, despite careful monitoring of the anti-clotting medication, bleeding may occur. Blood transfusions, surgery or stopping the ECMO treatment may be required to control bleeding. Bleeding may occur anywhere in the body, including the brain, which can cause permanent damage to your child, including brain injury. There are also bleeding risks associated with the surgical procedures to insert and remove the cannulas in the neck. Bleeding can result in death if it cannot be controlled.
- **Brain blood flow** - Placement of the cannulas into the neck usually involves permanently stitching shut the two major blood vessels, the carotid artery and the jugular vein, which may affect blood circulation in the brain. This usually does not cause serious problems because other blood vessels take over to supply adequate blood flow to the brain. There is a possibility of brain injury from stroke or bleeding during ECMO. There have already been risks for brain injury related to your child's illness, such as prolonged low blood oxygen levels and/or weak heart function. It may not be possible to determine brain injury prior to starting ECMO.
- **Blood vessel injury** - Injury to the arteries, veins, tissues and/or nerves can occur during the surgical procedure to insert the cannulas or during the ECMO treatment. This may result in bleeding and/or permanent long-term problems.
- **Blood transfusion** - Your child will be receiving blood transfusions. Please refer to the "Consent to Blood Transfusion" for further information.
- **Infection** - Whenever a catheter is inserted into the blood vessel, there is an increased risk of infection.



- **Air or blood clots** - Small clots or air bubbles can get into the blood stream of your child from the machine and block the flow of blood to the brain, organs, or the limbs. While some children have no problems with this, others may have significant long-term problems or death.



- **Equipment failure** - Although every precaution is taken and the ECMO staff is trained in troubleshooting and emergency procedures, the ECMO machine can malfunction. If this occurs, your child will be removed from the ECMO machine and placed back on conventional medical therapy. If the malfunction is easily corrected, your child may be able to go back on ECMO quickly.
- **Other unexpected complications may develop** - These will be discussed with you if they develop.
- **Failure to improve** - The ECMO machine works like an artificial lung and heart, allowing your child's lungs or heart to rest and heal. However, some children do not improve while on ECMO support. We will meet with you to discuss discontinuing ECMO should complications or failure to improve occur.



If two of the major blood vessels to the brain are used for the ECMO cannula, how will blood get to my child's brain?

The carotid artery and jugular vein on the left side of the neck, as well as other vessels, take over to supply blood to the brain. (These vessels take over the function of the others.) There sometimes are abnormalities in these vessels which prevent adequate blood flow to the brain, but that is very unusual. Most ECMO patients show no adverse effects from stitching off the carotid artery and jugular vein.

What is an intracranial hemorrhage?

Some children, especially premature babies, may develop abnormal bleeding in the head, also known as an intracranial hemorrhage (ICH). A head sonogram, or cranial ultrasound, is performed before and during ECMO to detect signs of an ICH in children who still have an open soft spot. If an ICH develops, we may need to discontinue ECMO. The head ultrasound cannot detect signs of brain injury. It also may not detect bleeding in all parts of the brain or the development of a stroke. Your child may require a Computerized Tomography Scan (CT Scan) during ECMO to assess signs of brain injury if indicated. A special test, a Magnetic Resonance Image (MRI), will be done before your child goes home to look more closely at their brain. However, even an MRI can't detect all brain injury. MRIs are unable to be performed while on ECMO.

Who is taking care of my child?

Once the decision to place your child on ECMO is made, a team of ECMO doctors, neonatologists, pediatric intensivists and surgeons will be in charge of their care. While your child is on ECMO, you will have a critical care nurse at the bedside and an ECMO specialist in charge of the ECMO machine. The ECMO specialist has completed specialized training in ECMO circuit management and emergencies. The ECMO core team is also in-house 24/7 to assist the bedside ECMO specialists, troubleshoot and perform ECMO circuit procedures. Cardiac perfusionists are also involved in the care of ECMO patients, specifically those patients that underwent open heart surgery in the operating room.

What will my child eat?

While on ECMO, most children do not receive food into their stomach. Special IV fluids, Total Parenteral Nutrition (TPN) and Lipids will be given. TPN provides high calories, vitamins and minerals; lipids provide essential fatty acids and calories. Some children on ECMO for several weeks might be given some feeding into their intestines through a tube inserted in the nose or mouth. Occasionally, children on ECMO who are awake and able to breathe without a breathing tube may be able to eat or drink by mouth. Each ECMO course is specific to each child and varying nutrition options will be discussed with you by your child's providers daily.

What support services are available for parents?

We realize it is very stressful and overwhelming to have a critically ill child, particularly when you are separated from home and family. Several resources are available to you during your child's hospitalization.

- **Emotional** - We strongly recommend you have a companion during your child's hospitalization. Please try to arrange for a support person - either a friend or relative - to accompany you. Within the first few days of ECMO therapy, you will be introduced to social workers and chaplains specifically trained in helping parents and families cope with the stresses involved. They are available to you at any time.

- **Financial** - Please feel free to discuss any concerns with the ECMO physicians, the ECMO Director, or a social worker. They will help you in any way possible.
- **Housing** - Many parents of Children's Mercy patients stay at the Ronald McDonald House, a home for families of critically ill children. Within walking distance of Children's Mercy, the house is inexpensive, pleasant, available for families from out of town, and has private rooms and baths, large kitchens and living spaces. The Ronald McDonald Family Room within Children's Mercy is available for all families. It is a "home away from home" for families who need a quiet place to go while not leaving the hospital. Several sleeping rooms are also available. If the Ronald McDonald House or Room does not work out or space is unavailable, we can suggest hotels that offer discounts to our families.
- **Spiritual** - The hospital chapel is close to the ICU and is always open. A chaplain is always on call; in emergencies, a parish priest or rabbi is also available. Our chaplains often visit patients and families. Several support services are available, including palliative care and interpreter services. Please let us know if you would like to speak with them.



Will my child have any special problems after ECMO?

Most children go home healthy and normal, as if they had never been sick. Babies may show no physical effects, but they may not behave like healthy newborns when they go home. Some babies tend to be less active, do not hold their heads up very well and seem to be “floppy.” Usually, this is only temporary and improves over the next few weeks. Some babies are slow to begin eating again, which can be frustrating for parents. Occupational therapists may be able to teach your baby to eat again. If your baby has some of these problems, remember they only mean your baby has been very sick. They do not necessarily mean your child isn’t developing appropriately.

Depending on your child’s particular heart and lung problems and any complications, your child may have some special needs. If so, we will teach you what you need to know before you leave the hospital.

What kind of follow-up care will my child need?

As your child gets steadily better and you prepare to go home, we start planning follow-up care. You will need to balance the joy of bringing a healthy child home with the reality that they have been critically sick. The lung or heart disease is better now, but your child was exposed to low oxygen levels before ECMO. This puts them at risk for developmental problems. Doctors can give you an idea of their concern for these problems before you go home. As your child grows, their medical providers will be able to monitor them for any developmental concerns.

Like other children, your child needs to see a pediatrician for check-ups and help when they are sick. If your child is under five years old, they will need to see a developmental specialist several times in the years before he or she starts school. Most children need only routine follow-up care. Children with breathing or feeding problems need to be seen more often. The developmental psychologist and pediatrician will pay special attention to your child’s growth, development, speech, hearing, and vision at appointments in the ECMO Follow-up Clinic.

ECMO Dictionary

Anticoagulant - Medication (blood thinner) that slows the formation of clots in the blood.

Arterial or venous blood gas (ABG/VBG) - A test done to determine the oxygen, carbon dioxide and acid levels in blood (arteries or veins).

Aorta - Large artery which carries oxygenated blood from the heart to the body.

Cannula (also called Catheter) - Tube that allows the removal or administration of fluid.

Cannulate - Procedure to insert a cannula into a part of the body - in this case, a vein or artery.

Carotid artery - A large artery in the neck which carries blood from the heart to the brain.

Decannulate - Procedure to remove a cannula.

Edema - Swelling; extra fluid in the tissues.

Femoral vein - Large vein in the groin which carries blood from the leg to the heart.

Flow - The measure of blood that circulates through the ECMO machine every minute.

Fresh Frozen Plasma (FFP) - Liquid part of the blood that contains proteins and essential blood clotting factors.

Head ultrasound - Sound wave test that is done to check for abnormal bleeding in the cranium or brain (intracranial hemorrhage).

Hyperoxia test - Indicates how the lungs are working in children with normal hearts.

Intracranial hemorrhage - Abnormal bleeding in the cranium or brain.

Intraventricular hemorrhage - Abnormal bleeding in the fluid-filled spaces (ventricles) of the brain.

Jugular vein - Large vein in the neck that carries blood from the brain to the heart.

Lipids - Intravenous fat solution given to children unable to eat by mouth for a long period of time. Provides essential fatty acids for nutrition.

Oxygenate - To combine or supply with oxygen. When oxygen is added to blood, as it is in the lungs, the blood becomes oxygenated.

Oxygenator - The artificial lung within the ECMO circuit that puts oxygen into the blood and removes carbon dioxide.

Platelets - Cells in the blood that aid in clotting.

Pump - Device that circulates the blood through the ECMO machine.

Respirator (ventilator) - Machine that assists with breathing.

SCUF - a filter in the ECMO machine that can be used to help remove extra fluid from the child's body to decrease swelling and edema.

Sweep gas - the gases that are delivered to the membrane oxygenator to provide oxygen. This is usually just a percentage of oxygen, but carbon dioxide can be added when needed.

Trial off - a test period when your child is clamped off ECMO, while the cannula(s) remain surgically in place. Their ventilator settings will be increased to support them during this time. Blood tests will be done to determine how your child tolerates not being on ECMO. If this is done, it is usually done after your child has been on ECMO several days.

Ultrasound (also called ECHO) - Sound waves that allow the physician to "see" inside the body, used to examine the head, heart, or abdomen.

Unoxygenated blood - Blood that has delivered most of its oxygen to body tissues and is returning back to the heart. Blood in the veins is unoxygenated.

Venoarterial ECMO (VA ECMO) - Type of ECMO in which blood is drained from the heart (usually through the jugular vein) and put back into the aorta, generally through the carotid artery.

Venovenous ECMO (VV ECMO) - Type of ECMO in which blood is drained from the heart (usually through the jugular vein) and put back into the heart, most often through one specially divided cannula.

Ventilate - Removal of carbon dioxide from the blood.

Ventilator - See Respirator.

Weaning - Process of slowly removing a treatment or support from the child. Can refer to ECMO, the ventilator or medications. The time when the amount of oxygen in the child's blood is high enough that the blood flow through the ECMO machine can be steadily decreased without affecting the oxygenation is called "weaning."

The Children’s Mercy ECMO team gratefully acknowledges contributions to this ECMO Parent Information Manual from the Extracorporeal Life Support Organization, a non-profit, voluntary organization of ECMO caregivers.

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