



# ECMO PARENT HANDBOOK



**UNIVERSITY OF VIRGINIA  
CHILDREN'S HOSPITAL  
ECMO TEAM**





UVA Children's Hospital



DEAR PARENTS, FAMILY AND FRIENDS,

We understand this is a very difficult and overwhelming time for you and your family. This booklet is provided to give you information on ECMO (Extracorporeal Membrane Oxygenation) and provide some answers to questions you may have regarding ECMO.

Please feel free to ask questions or express your concerns. The Health Care Team Members are here to help meet the needs of you and your child. There are many people here to help you, including the ECMO Clinicians, Physicians, Nurses and Respiratory Therapists, all of whom are familiar with the care of critically ill children.

Sincerely,

THE ECMO TEAM

UNIVERSITY OF VIRGINIA CHILDREN'S HOSPITAL

PICU: 434-924-1761

NICU: 434-924-2335

## TABLE OF CONTENTS

1.	WHAT IS ECMO?	PAGE 5
2.	DOES MY CHILD NEED ECMO?	PAGE 5
3.	WHO IS ON THE ECMO TEAM?	PAGE 5
4.	HOW DOES ECMO WORK?	PAGE 6
5.	WHAT HAPPENS ONCE YOUR CHILD IS ON ECMO?	PAGE 6
6.	POTENTIAL COMPLICATIONS OF ECMO	PAGE 7
7.	PARENT'S ROLE IN ECMO	PAGE 7
8.	COMMON ECMO TERMS AND TESTS	PAGE 8

## **WHAT IS ECMO?**

ECMO is a special procedure called **ExtraCorporeal Membrane Oxygenation**. ECMO is a life saving, temporary support of heart and/or lung function using mechanical devices. ECMO uses an artificial heart-lung machine similar to the one used for open heart surgery. Once your child is placed on ECMO, the ECMO machine will take over the work of your child's heart and/or lungs, providing oxygenation and ventilation (removing carbon dioxide). The ECMO machine gives a sick heart and/or lungs the chance to rest and heal. In rare cases, ECMO may not always help the heart/lungs recover. Since ECMO can not be used indefinitely, the doctors and ECMO team would talk with you and your family about treatment options. While your child is on ECMO, they will be given medication (sedatives) in order to be kept comfortable and reduce their movement. Your child will also have a breathing tube in, so they will be unable to talk.

## **DOES MY CHILD NEED ECMO?**

ECMO is a treatment option when your child is very sick with heart failure or severe lung disease. When the heart and lungs work well they allow blood to pick up oxygen from the lung, exhale waste gases like carbon dioxide and pump the oxygenated blood to the body. When the heart is sick or injured, it is unable to pump enough blood to the body. When the lungs are sick or injured, oxygen supply may be less than what your child's body needs.

Mechanical ventilation and medications can only help so much. Sometimes the heart and/or lungs of the child are too sick to respond to these options. Your child is one of those few who are not responding to usual treatments and will need to be placed on ECMO.

## **WHO IS ON THE ECMO TEAM?**

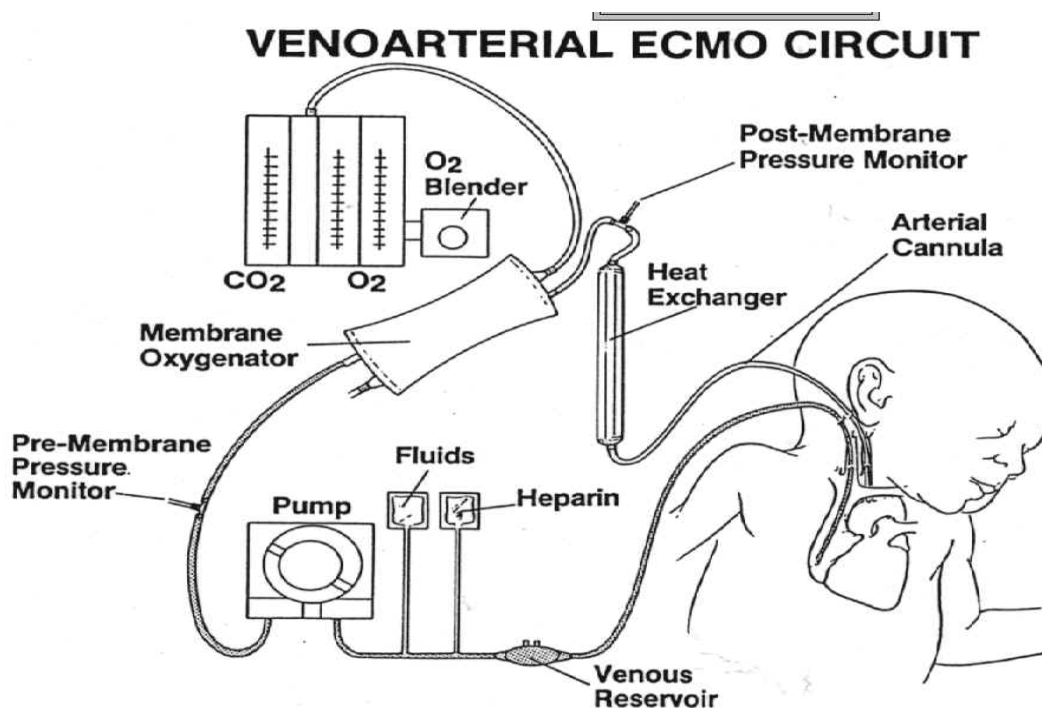
The ECMO Team caring for your baby is made up of Neonatologists or Pediatric Intensivists, Pediatric Surgeons, or Cardiothoracic Surgeons, Cardiologists, ECMO Clinicians, ICU Nurses and Respiratory Therapists. University of Virginia Children's Hospital is a teaching hospital therefore your child will also have Interns, Residents and Fellows following your child's care. All the members of the ECMO Team are here to answer any questions or concerns you may have.

At all times your child will have two caregivers:

1. The ICU Bedside Nurse
2. ECMO Clinician
  - The ECMO clinicians consist of perfusionists, respiratory therapists and intensive care nurses, educated in the functioning of the ECMO machine.

## HOW DOES ECMO WORK?

The surgeon will place plastic tubes (cannulae) into your child's neck and/or chest. These tubes allow blood to be taken from your child's body and into the ECMO circuit. The oxygenator (or artificial lung) of the circuit will provide oxygen and remove carbon dioxide. The blood will then pass through a heat exchanger, which warms the blood before it re-enters the body. The oxygenated blood is then returned to the body via a tube (cannulae). A member of the ECMO team will be able to answer questions you may have regarding the machine.



Source: *University of Glasgow, Department of Surgical Paediatrics, The Royal Hospital for Sick Children, Glasgow.*

## WHAT HAPPENS ONCE YOUR CHILD IS ON ECMO

At the beginning of ECMO, the ECMO machine does most of the work for your child's heart and lungs. Even though your child's status might improve, it is important to remember that the ECMO machine is doing the work of their heart and lungs. As your child's heart and/or lung functions improve, we will begin to slowly turn down the ECMO machine. This is called weaning. The machine is turned down until the machine is doing very little work and your child's heart and lungs are taking over.

Each child is different, which will affect how long they will need ECMO. Some children need a few days on the ECMO machine; some need much more time for their heart and lungs to heal. Some of the differences include the following: the type of heart or lung disease, the amount of damage to the heart and/or lungs before ECMO, and complications which may occur during ECMO.

## POTENTIAL COMPLICATIONS OF ECMO

1. Bleeding:  
This may occur due to heparin, which is a medication necessary to prevent blood clotting. The most serious place in which bleeding may occur is in the brain. Any bleeding will be monitored while on ECMO.
2. Blood Transfusion Complications:  
Your child will be receiving transfusions of blood, and other blood products from the hospital's blood bank. Your child will be monitored for any signs of complications.
3. Small blood clots or air bubbles:  
These can get into the blood stream of the patient from the machine. The ECMO clinician will monitor the machine for problems.

## PARENT'S ROLE IN ECMO

- We understand the importance of visits from family and friends. Parents and family members are welcomed to visit while their child is on ECMO. *Please note the visitation policy of the unit your child is in.* All visitors are asked to use the phone outside the NICU and PICU doors to announce your presence before entering.
- You can interact with your child through light touch or talking. It is important not to over stimulate your child in order to minimize movement. We encourage you to ask the ECMO clinicians, nurses or physicians any questions you may have about your child's care.
- Remember to take care of yourself. Make sure you eat properly and get enough sleep. Please do not feel that you must remain at your child's bedside at all times. You can call the unit at anytime to see how your child is doing.

## COMMON ECMO TERMS AND TESTS

**Antibiotic:** A drug that destroys bacteria or germs. Used to prevent or treat an infection.

**Aorta:** The large artery which carries oxygenated blood from the heart to the body.

**Arterial Cannula:** Tubes that will carry the blood away from the patient to the heart-lung machine and return the blood from the heart-lung machine to your child.

**Breathing Tube:** A temporary tube that goes into your child's nose or mouth to their lungs and breathes air or oxygen for your child (this is also called artificial breathing). You can also give some medications, like sedatives, through this tube.

**Cannula:** A large tube you can give or take fluid out of.

**Catheter:** See cannula

**Cannulate:** To insert a cannula into a vein, an artery or the heart.

**Carbon Dioxide:** A colorless, odorless gas. It is a waste product made by the body. Carbon dioxide travels in the blood from the body's tissues to the lungs. Breathing out clears carbon dioxide from the lungs.

**Cardiac:** Refers to the heart.

**Cardiologist:** A physician specializing in the diseases of the heart.

**Cardiothoracic Surgeon:** A surgeon who operates only on the heart and chest.

**Carotid artery:** Large artery in the neck which carries blood from the heart to the brain.

**Chest tube:** A tube that is placed into the space between your child's lung and chest wall and allows air or fluid to drain out of your child. Used to treat a collapsed lung (pneumothorax).

**Chest X-ray:** An X-ray or picture to look at the lungs and heart. A radiologist and/or physician will read a chest X-ray.

**CO<sub>2</sub>:** An abbreviation for carbon dioxide.

**Decannulate:** To remove a cannula.

**ECHO:** Echocardiogram - A procedure similar to a head ultrasound which uses sound waves to look at the heart to see the structures and how well the heart is functioning. A cardiologist reads the picture made by the ECHO.

**EEG:** Electroencephalogram - A tracing of the electrical activity of the brain. Electrodes are placed on the scalp in several locations with glue. The electrodes are removed gently with special solution. A neurologist reads the tracing.

**Fluids:** Liquids such as blood products, saline, or albumin that are used to help your child and the ECMO machine.

**Head Ultrasound:** A painless procedure that uses sound waves to look at brain tissue. Gel is placed on top of your child's head and a small device takes a picture of the brain. This picture is read by a radiologist.

**Heat Exchanger:** Warms the blood to body temperature before returning it to your child.

**Hemofiltration:** An artificial kidney which may be used to remove excess fluid and waste.

**Heparin:** A drug that helps prevent blood clots from forming. It belongs to the family of drugs called anticoagulants (blood thinners).

**ICU:** Intensive Care Unit

**Infection:** An invasion of the body by bacteria or a virus.

**Intracranial (or intraventricular) hemorrhage:** Abnormal bleeding in brain or head. (Abbreviated ICH or IVH).

**Meconium:** The first stool of the newborn infant. May be present in the amniotic fluid at birth.

**Meconium aspiration:** Small particles of meconium become lodged in the lungs, preventing oxygen from reaching the areas of gas exchange. Depending on the amount and location of blockage, this can cause mild to severe respiratory distress.

**Membrane Oxygenator:** A device used to add oxygen to and remove carbon dioxide from the blood.

**MRI/MRA:** Magnetic Resonance Imaging - A technique that uses a magnetic field to obtain pictures of the brain. It is believed to be safer than the radiation used in conventional X-Rays. Sedation maybe required as movement interferes with the test.

**Neonatologist:** A doctor specializing in newborn intensive care.

**Neurologist:** A doctor specializing in the brain and the nervous system.

**O2:** An abbreviation for oxygen.

**O2 Blender:** Device that blends pure oxygen with medical air.

**Oxygen:** A tasteless, odorless, colorless gas needed for breathing and to sustain life.

**Oxygenate:** To combine or supply with oxygen. When oxygen is added to blood, as in the lungs, it becomes oxygenated. Also called arterial blood.

**Pediatric Intensivist:** A doctor who specializes in the care of critically ill children, usually in the PICU (Pediatric Intensive Care Unit).

**Pediatric Surgeon:** A doctor who specializes in surgery performed on children.

**Persistent Fetal Circulation (PFC/PPHN):** In the uterus, the mother supplies the fetus with oxygen through the umbilical cord. The lungs do not oxygenate the blood until the baby is born. At birth, the circulation must change from fetal to newborn circulation, allowing the blood to pass through the lungs to be oxygenated. If this fails to occur, the blood remains circulating as it did in the fetal state, and the baby's body will not get enough oxygen. Also called persistent pulmonary hypertension or PPHN.

**Platelets:** Cells in the blood that help the blood clot.

**Pneumothorax:** Escape of air from the lung into the space between the lung and chest wall, usually resulting in lung collapse.

**Pre and Post Membrane Pressure Monitor:** A way to monitor the pressure entering and leaving the oxygenator.

**Pump:** This device circulates the blood through the circuit and returns it to your child. Pump flow refers to the amount of blood being pumped through the circuit.

**Radiologist:** A doctor who specializes in reading and understanding x-rays and other tests.

**Respiratory distress:** Difficulty breathing. This may be caused by foreign material in the lungs or if the lungs are not done developing. It may be necessary to give your child additional oxygen or a ventilator.

**Respiratory distress syndrome (RDS):** This is a diagnosis sometimes made if your child has immature lungs (not fully developed) and difficulty breathing. Also known as surfactant deficiency (see definition of surfactant).

**Sedatives:** A kind of medication given to your child to help keep them comfortable and decrease their movement. This medicine makes your child sleepy.

**Sepsis:** An infection in the blood.

**Surfactant:** A soap-like substance normally found in the lungs of full-term babies, children and adults. Presence of this substance keeps the lungs from collapsing. Premature babies may not have enough surfactant to keep their lungs from collapsing.

**Unoxygenated blood:** Blood that has delivered most of its oxygen to the tissues of the body and is therefore low in oxygen, or poorly oxygenated. Also called venous blood.

**Veno-arterial ECMO:** Blood is drained from the heart through the jugular vein and returns to the aorta via the carotid artery.

**Veno-veno ECMO:** Venous blood is drained and oxygenated and returned into the venous circulation.

**Venous Reservoir:** A reservoir that collects blood drained from the venous circulation.

**Ventilator:** Breathing machine used to put oxygen into the lungs through a tube in the windpipe.  
Also called a "respirator".

**Weaning:** ECMO blood flow rate will be decreased gradually as the lungs improve.

**NOTES:**

